HEALTH INFORMATION SYSTEMS

HEARINGS

BEFORE THE

SUBCOMMITTEE ON SCIENCE, RESEARCH AND TECHNOLOGY

AND THE

SUBCOMMITTEE ON NATURAL RESOURCES, AGRICULTURE RESEARCH AND ENVIRONMENT

OF THE

COMMITTEE ON SCIENCE AND TECHNOLOGY
U.S. HOUSE OF REPRESENTATIVES

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HEALTH INFORMATION SYSTEMS

TUESDAY, JUNE 2, 1981

HOUSE OF REPRESENTATIVES, COMMITTEE ON SCIENCE AND TECHNOLOGY, SUBCOMMITTEE ON SCIENCE, RESEARCH AND TECHNOLOGY; SUBCOMMITTEE ON NATURAL RESOURCES, AGRICULTURE RESEARCH AND ENVIRONMENT,
Washington, D.C.

The subcommittees met, pursuant to call at 9 a.m., in room 2325 of the Rayburn House Office Building, Hon. James Scheuer and Doug Walgren (chairmen of the respective subcommittees) presiding.

Mr. WALGREN. The committee will begin its hearings on the information data in the health area. We have two subcommittees that are particularly interested in this question. Today we will be listening to witnesses who will be responding to specific questions about activities that are specifically and uniquely a health problem. However, in the broader context it is a consideration of a specific case related to the general problem of information and how to extract from that information the details necessary to our life and well-being. This is a problem of immense proportions and will only be solved by patient and careful consideration and planning. In that respect health information systems becomes a subject for review by this subcommittee.

Since the advent of computers, our ability to extract and collect information has grown rapidly. We are presently being buried in data, not always the right kind and often not of the best quality. It has been suggested that perhaps only 33 percent of the information gathered is ever utilized or analyzed. The remainder is either lost, discarded, or never utilized because of bad planning or accessibility problems.

It appears as if our approach to the problem of health data collection is decentralized and uncoordinated as it also is in other areas of information collection. Congress is not blameless in fostering this approach since legislation often contains requests for information collection without regard to coordination with previous requests. We must begin to be concerned with this lack of coordination as we enter this new age of the information revolution.

I hope that by your presence today and of those others, that we will hear on ensuing days of this hearing, that we will begin to achieve some level of awareness and some direction to begin planning for the better and more efficient use of information. A start must be made—and soon.

I greatly appreciate having Congressman Scheuer, chairman of the Subcommittee on Natural Resources, Agriculture Research and Environment, join us today since he has long been active and had interest in the use of computers in health care.

I would like to at this point turn to Mr. Scheuer for any opening comments he might have.

Mr. SCHEUER. Thank you, Mr. Chairman. I appreciate your cooperation and involvement in setting up these hearings which of course are the second of our quadrennial hearings on the computer and health care. I am happy to welcome as our lead witness Dr. Joyce Lashof who is one of our very star witnesses 4 years ago. The Congress is very much concerned that we are missing a great bet in the involvement of the computer in health care first as to control of escalating health care costs that we were bemoaning when they were $150 or $160 million a year 4 years ago. Now they are approximately $220 million a year and they seem to be as far from rationalization. We seem to be as far from getting an extended reach over health care costs as we were 4 years ago. Second, we are interested in the potential of the computer as a diagnostic aid, as an aid in the diagnostic care of patients.

We thought 4 years ago that the computer properly rationalized and properly controlled could virtually revolutionize the organization of health care in this country as well as the policy of health care bringing excellence of health care to remote areas, to slum areas where it is difficult to get top quality professionals to settle down full time and it was our hope that through the elaboration of telecommunications and the computer we could bring extraordinarily sophisticated diagnostic teams to areas where that had not been available in the past.

We are still hopeful that can be done. We are disappointed at the rate of progress. I suppose the purpose of the hearings today is to find out whether we were wrong in the high hopes we held out for the computer as an aid in getting a handle on cost effectiveness and rationality and elaboration of health care services as well as an aid in actually improving the quality of health care services vis-a-vis the individual patient and the diagnostic capability and the extraordinary memory capability that the computer could summon. There are already 300 activities dealing with the collection of health care statistics supported by the Department of Health and Human Services. There seems still to be minimal coordination, there seems still to be limited access to this data. Congressman Walgren and Congressman Shamansky and Congressman Brown and I are all concerned that this lack of coordination continues 4 full years after our first effort to produce rationality in this field.

We look forward to the day when we will have a national coordinated system, the application of the computer to health care and this second set of hearings hopefully will be an incremental step down that road. I am delighted to welcome again Dr. Joyce Lashof. Dr. Lashof was appointed Assistant Director of the Office of Technology Assessment responsible for the Health and Life Sciences Division beginning September 8, 1978.

From July 1977 until her appointment Dr. Lashof was Deputy Assistant Secretary of Health, Education, and Welfare.

A Phi Beta Kappa graduate of Duke University, Dr. Lashof earned her M.D. degree from Woman's Medical College of Pennsylvania. She interned and held residences in hospitals in New York

City. And I guess New York City has left our stamp of excellence on her. We are delighted to have you, Dr. Lashof and look forward to your testimony. It will be printed in full at this point in the record and perhaps you might want to speak informally to us for 10 or 15 minutes and then we will have questions.

Mr. **Walgren**. Dr. Lashof, would you withhold 1 second. I wanted to give George Brown, whom all of you know has had continuing interest in the question of information gathering, an opportunity to contribute before we begin.

Mr. **Brown**. If you have no objection I will insert my excellent remarks in the record at this point.

Mr. **Walgren**. Thank you, Mr. Brown.

[The opening remarks of George Brown follow:]

OPENING REMARKS
HONORABLE GEORGE E. BROWN, JR.
JUNE 2, 1981
HEALTH INFORMATION HEARING

THANK YOU MR. CHAIRMAN. FIRST I COMPLIMENT YOU AND MR. SCHEUER FOR HOLDING THIS HEARING SINCE WE FACE A REAL PROBLEM, NOT ONLY IN HEALTH INFORMATION BUT IN THE WHOLE AREA OF INFORMATION POLICY AND PLANNING.

TODAY WE BEGIN THREE DAYS OF HEARINGS THAT WILL LOOK AT THE ISSUES, NEEDS AND PROBLEMS RELATED TO THE DEVELOPMENT OF A COORDINATED HEALTH INFORMATION SYSTEM. AS PRESENTED, THERE IS NO SPECIFIC LEGISLATION INVOLVED. ALTHOUGH IT IS AN INFORMATIONAL HEARING THERE IS EVERY REASON TO GIVE IT OUR UTMOST ATTENTION SINCE IT REPRESENTS AN EXTREMELY BROAD POLICY AREA WITH IMMENSE POTENTIAL TO IMPROVE THIS NATION'S ABILITY TO DO MEDICAL RESEARCH, PROVIDE INSIGHTS FOR BETTER HEALTH PLANNING, ASSIST IN ATTAINING BETTER CONTROL OF RISING HEALTH CARE COSTS, STIMULATE GREATER INTEREST IN THE DEVELOPMENT OF A HEALTH CARE SYSTEM IN CONTRAST TO OUR PRESENT DISEASE CARE SYSTEM, AND EVEN PROVIDE ACCESSIBLE AND ADEQUATE DATA TO ENABLE MEDICAL EDUCATORS THE MEANS OF IMPROVING AND MAINTAINING COMPETENCY IN THEIR SPECIALTY.

THERE ARE OTHER EXAMPLES THAT ONE COULD CHOOSE TO EMPHASIZE THE NATION'S NEED FOR A COHESIVE INFORMATION POLICY.

THIS WAS IN FACT RECENTLY THE TOPIC OF A HEARING RELATED TO A BILL, H.R. 3137 I INTRODUCED PERTAINING TO THE DEVELOPMENT OF AN INFORMATION POLICY INSTITUTE. OTHER EXAMPLES INCLUDE THE NUTRITION STATUS MONITORING SYSTEM -- TO BE EXAMINED LATER THIS MONTH, AND THIS AFTERNOON THE DORFA SUBCOMMITTEE WILL BEGIN LOOKING INTO THE STATUS AND CONTENT OF EXISTING RESOURCE DATA BASES MAINTAINED BY THE USDA.

IT SHOULD BE POINTED OUT THAT TODAY'S HEARINGS, IN A REAL SENSE, REPRESENT AN EXTENSION OF HEARINGS HELD IN 1978 BY PAUL ROGERS. THESE HEARINGS RESULTED IN PASSAGE OF P.L. 95-623 WHICH CREATED THE NATIONAL CENTER FOR HEALTH CARE TECHNOLOGY AND FOR THE SECOND TIME IN FOUR YEARS GAVE THE NATIONAL CENTER FOR HEALTH STATISTICS A STRENGTHENED RESPONSIBILITY TO ACT AS A CLEARINGHOUSE FOR HEALTH STATISTICS, PARTICULARLY IN THE AREA OF THE EFFECTS OF THE ENVIRONMENT ON HEALTH. UNFORTUNATELY THIS MANDATE HAS NEVER BEEN FULLY ADHERED TO OR CARRIED OUT.

ALL OF THESE PROBLEM AREAS HAVE INFORMATION AS THEIR COMMON DENOMINATOR AND THE NEED FOR BETTER APPROACHES TO HANDLE THE INFORMATION EXPLOSION THAT HAS RESULTED FROM OUR IMPROVED METHODS OF COLLECTING DATA.

I SHARE THE VIEW EXPRESSED BY THE CHAIRMAN THAT WE MUST BEGIN TO CONCERN OURSELVES WITH A PLANNING PROCESS THAT WILL PROVIDE A CLEARER DIRECTION AND A COHERENCE TO THE MANNER IN WHICH INFORMATION LIKE HEALTH DATA IS COLLECTED. I AM CONVINCED THAT IN ORDER TO INSURE A HEALTHIER FUTURE OF OUR CITIZENS WE MUST PAY CLOSER ATTENTION TO OBTAINING BETTER DATA CONCERNING BOTH THE INFLUENCE OF OUR ENVIRONMENT ON HEALTH AND IN THE AREA OF EPIDEMIOLOGICAL DATA.

CERTAINLY WITHIN THE NEXT THREE DAYS OUR WITNESSES WILL BE ABLE TO GIVE US THE INFORMATION WE NEED TO START THE PLANNING.

I LOOK FORWARD TO HEARING YOUR VIEWS.

Mr. WALGREN. We have a new Member in Congress this year who has been because of his background and inate interest in communications, very interested in this committee's work and I would like to give Mr. Shamansky an opportunity to add anything he wishes.

Mr. SHAMANSKY. I am not even going to have my excellent remarks inserted in the record.

Mr. WALGREN. Dr. Lashof we are pleased you are here. With the welcome Mr. Scheuer has given you, please proceed.

STATEMENT OF DR. JOYCE LASHOF, ASSISTANT DIRECTOR, HEALTH AND LIFE SCIENCES DIVISION, OTA

Dr. LASHOF. Thank you. Thank you Congressman Scheuer for that introduction. I am accompanied today by Dr. Michael Gough, project director for OTA Study on Technologies for Determining Cancer Risks from the Environment. I will be drawing from that study to illustrate some of the value as well as needs and shortcomings in our health data systems. As you indicated I will summarize my testimony and try to highlight some specific features for you. The OTA health program has been interested in the problem of health statistics and health information over the years and has released three reports dealing with this. The first one, the "Policy Implications of Medical Information Systems" was released in 1977 and addressed the benefits and limitations of such systems; the report, "Computer Technology in Medical Education and Assessment," released in September 1979, describes the current uses of computers in medicine and summarizes the impact of computer technology on medical education; and the report, "Selected Topics in Federal Health Statistics," released in June 1979, addressed the data systems used in Federal health programs. All of these reports have been made available to staff, and additional copies are available to any member of the committee that wishes them.

Today I will highlight only a few findings from the Federal health statistics study and then I will illustrate the use of various data sources and record systems in the study of cancer. For the latter I will draw upon the OTA study, "Technologies for Determining Cancer Risks from the Environment," which will be released later this month.

The Federal health statistics study examined the health data activities of HHS and seven other Federal agencies and reviewed legislation which required the collection of health data.

We found that the Public Health Service (PHS) administers 153 individual data projects, the Health Care Financing Administration (HCFA) operates at least 13 large statistical projects, and several other agencies and departments outside the Department of Health and Human Services (DHHS) also conduct major health statistical activities. These many programs acquire health information for program management and evaluation, development of regulations, and for policymaking.

Our review of legislation revealed that 169 authorities, statutes or sections, directly or indirectly specify some action that results in health data collection. Of the 169, 60 specifically mandate the initiation of a data collection system or identify data to be collected. A complete listing of these authorities and their requirements is included in our report. It became clear that our health data system has developed over the years as a result of multiple, often disparate, requirements and that although the elements of a traditional health information system exist, coordination and linkages will be necessary before an effective integrated information system becomes a reality.

Examples of data availability, data usefulness, and data needs are well illustrated by our cancer study. Let me review some of those for you.

Both mortality and incidence data are useful for studying and understanding cancer in our society. Mortality data, which have been collected for the entire United States since 1933, are considered far more reliable than are incidence data, which have only recently begun to be collected in a systematic fashion.

The surveillance, epidemiology and end results (SEER) program, administered by the National Cancer Institute (NCI), is the first attempt in this country to record new cancer cases, continuously, for a sample of the entire population. The SEER program began in 1973, and about 10 percent of the U.S. population resides in areas covered by SEER registries.

Of serious concern, however, and well recognized by NCI, is that certain subgroups, such as the black population, are not represented sufficiently to provide reliable rates. This is troublesome because cancer mortality rates and trends for blacks differ considerably from those for whites, and are for the most part higher and rising faster. With increased funding this problem of poor incidence data for blacks could be remedied by expanding SEER to include areas with large black populations.

The identification of cancer cases in the SEER program combined with the determination of survival rates in the end results part of the program allows NCI to measure the effectiveness of various forms of treatment. This effort is especially important now when new treatments are being introduced, and the prognosis for cancer patients is thought to be improving.

Mortality data are collected by NCHS, but in the course of our "cancer assessment" we experienced first hand the effects of limitations on data availability. OTA wanted to study site-specific cancer mortality from 1933 onward. NCHS, because of other demands on its resources, has computerized mortality data only for the last 10 years, making it necessary for OTA to computerize the first 35 years. With the help of NCHS and considerable effort, we prepared a computer tape with all cancer mortality data from 1933 to 1978, which we will make available to interested researchers.

A recent major improvement concerning mortality data is the national death index. NDI, administered by NCHS, is designed to provide medical and health researchers with probable fact of death, the death certificate number, and the location of the death certificate, for deaths occuring in 1979 or later, when supplied with a minimum set of identifiers (generally the person's name and either social security number or date of birth).

NDI will be of immediate use in ongoing long-term studies which include mortality. This has been described as the most important recent advance in making vital statistics accessible to researchers. NCI's SEER program plans to use NDI to determine deaths of all persons in the SEER registries. This should reduce the number of people lost to followup by SEER and provide better information about survival.

In addition to mortality and incidence data we want to obtain information concerning factors that cause disease or increase the risk of a disease. A number of sources are helpful in this regard.

NCHS conducts several general-purpose surveys that provide statistics about the health status of the U.S. population. One of these is the health interview survey (HIS) which is the principal source of information on the health of the civilian noninstitutionalized population. Each year, approximately 40,000 households containing about 120,000 persons are sampled. NCHS is currently using HIS to conduct a pilot study on cancer costs.

Another NCHS survey, the health and nutrition examination survey (HANES), initiated in 1970, is the most extensive national assessment of the health and nutritional status of the American people. Two surveys have been conducted, examining a total of about 40,000 people. These surveys collect data from interviews and physical examinations to estimate the prevalence of chronic diseases, establish physiological standards for various tests, determine the nutritional status of the population, and assess exposure levels to certain environmental substances.

HANES surveys might become valuable sources of information for cancer epidemiology if sufficient resources were available. Because of its representative nature, aggregate data from the survey can be used to represent normal or background levels. For example, white cell count levels determined in HANES I were used for comparative purposes in an epidemiologic study of laboratory workers exposed to suspected toxic chemicals. HANES II contains certain information about dietary intake of substances which have been associated with a lower risk of cancer—vitamins A and C—and substances such as fats, which are associated with higher risks. NCHS, with its HANES capabilities, was asked to participate in studies near Love Canal, and to evaluate the health status of certain high-risk industry groups, but was unable to do so because of limited resources.

HANES might be linked with other health data systems, such as the national death index, to facilitate assessment of whether particular exposure levels or certain nutritional statuses are associated with cancer mortality.

Many Government records, other than those maintained expressly for health purposes, may be important sources of data for researchers looking for associations between exposures and disease states. The Social Security Administration (SSA), Internal Revenue Service (IRS), Veterans' Administration (VA), the Bureau of the Census, and NCHS are organizations with extensive data collections.

Individuals in several Government agencies have been promoting a linked administrative statistical sample (LASS), a pilot project designed to bring together records of the IRS, SSA, and NCHS. The project planners aim to provide an improved data base for mortality research by compiling statistical information from the participating agencies on a sample of individuals. The starting point will be the 1 percent continuous work history sample of the SSA. This effort is a prototype for linked systems that may be useful in future studies of cancer mortality, particularly the contributions of occupational exposures.

As you can see a large pool of data, from many sources, is essential if we are to understand what is happening in cancer today, and similar data are needed to aid our understanding of other chronic diseases. Much different information is needed to understand our health care system—data on resources, manpower, and facilities, data on costs, and data on utilization and impact of technology. As new approaches to structuring our health care system are explored it would seem appropriate that the adequacy of our health data system also be addressed.

I will be happy to answer questions.

[The prepared statement of Dr. Lashof follows:]

Testimony of Joyce C. Lashof, M.D.

before

Science, Research and Technology Subcommittee

and

Natural Resources, Agriculture Research and Environment Subcommittee

of the Committee on Science and Technology

U.S. House of Representatives

June 2, 1981

I am Dr. Joyce Lashof, Assistant Director, OTA. Accompanying me today is Dr. Michael Gough, Project Director for the OTA study on Technologies for Determining Cancer Risks from the Environment.

I am pleased to testify as to the needs and benefits of health data and health information systems. The OTA health program has addressed this issue in a number of reports. Our report, Policy Implications of Medical Information Systems, released in 1977 addressed the benefits and limitations of such systems; the report, Computer Technology in Medical Education and Assessment, released in September 1979, describes the current uses of computers in medicine and summarizes the impact of computer technology on medical education; and the report, Selected Topics in Federal Health Statistics, released in June 1979, addressed the data systems used in Federal Health Programs. All of these reports have been made available to staff, and additional copies are available to any member of the Committee that wishes them.

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The Federal Health Statistics study examined the health data activities of HHS and seven other federal agencies and reviewed legislation which required the collection of health data.

We found that the Public Health Service (PHS) administers 153 individual data projects, the Health Care Financing Administration (HCFA) operates at least 13 large statistical projects, and several other agencies and departments outside the Department of Health and Human Services (DHHS) also conduct major health statistical activities. These many programs acquire health information for program management and evaluation, development of regulations, and for policymaking. Our report and the report of an evaluation of the Cooperative Health Statistics System (CHSS) of the National Center for Health Statistics (NCHS) describe the capabilities of the various data systems as well as the problems to be faced in developing a national health information system.

Our review of legislation revealed that 169 authorities (statutes or sections) directly or indirectly specify some action that results in health data collection. Of the 169, sixty specifically mandate the initiation of a data collection system or identify data to be collected. A complete listing of these authorities and their requirements are included in our report. It became clear that our health data system has developed over the years as a result of multiple, often disparate, requirements and that although the elements of a traditional health information system exist, coordination and linkages will be necessary before an effective information system becomes a reality.

Examples of data availability, data usefulness and data needs are well illustrated by our cancer study. Let me review some of those for you.

Both mortality and incidence data are useful for studying and understanding cancer in our society. Mortality data, which have been collected for the entire U.S. since 1933, are considered far more reliable than are incidence data, which have only recently begun to be collected in a systematic fashion.

The Surveillance, Epidemiology and End Results (SEER) program, administered by the National Cancer Institute (NCI), is the first attempt in this country to record new cancer cases, continuously, for a sample of the entire population. The SEER program began in 1973, and about 10 percent of the U.S. population resides in areas covered by SEER registries. Although SEER experienced problems common to the start-up of any large incidence data collection system -- the inclusion of preexisting as well as new cancer cases, and different levels of cooperation and understanding of the program -- all indications are that the system is working well and will continue to improve.

Of serious concern, however, and well recognized by NCI, is that certain subgroups, such as the black population, are not represented sufficiently to provide reliable rates. This is troublesome because cancer mortality rates and trends for blacks differ considerably from those for whites, and are for the most part higher and rising faster. With increased funding this problem of poor incidence data for blacks could be remedied by expanding SEER to include areas with large black populations.

The identification of cancer cases in the SEER program combined with the determination of survival rates in the End Results part of the program allows NCI to measure the effectiveness of various forms of treatment. This effort is especially important now when new treatments are being introduced, and the prognosis for cancer patients is thought to be improving.

Mortality data are collected by NCHS, located within the DHHS Office of Health Research, Statistics, and Technology (OHRST), which since 1960, has played a major role in the development of national health statistics policy and programs. The Division of Vital Statistics collects information on natality, mortality, marriage, and divorce from the individual States and regions.

In the course of our "Cancer Assessment" we experienced first hand the effects of limitations on data availability. OTA wanted to study site-specific cancer mortality from 1933 onwards. NCHS, because of other demands on its resources, has computerized mortality data available only for the last 10 years, making it necessary for OTA to computerize the first 35 years. With the help of NCHS and considerable effort, we prepared a computer tape with all cancer mortality data from 1933 to 1978, which we will make available to interested researchers.

A recent major improvement concerning mortality data is the National Death Index. Deaths in the United States are registered by the States or other death registration areas (e.g., District of Columbia). The records are transmitted on microfilms or on magnetic tape to NCHS for compilation. Historically, because there was no integration of records for the country as a whole, no mechanism had existed at the national level to determine if a person had died. In 1981, after several years of planning and preparation, the National Death Index (NDI) will be placed into operation to serve that purpose.

NDI, administered by NCHS, is designed to provide medical and health researchers with probable fact of death, the death certificate number, and the location of the death certificate, when supplied with a minimum set of identifiers (generally the person's name and either social security number or date of birth). The researcher then may contact the registration area where the possible match has occurred to obtain the death certificate or the required information.

NDI will be of immediate use in ongoing long-term studies which include mortality. The NDI has been described as the most important recent advance in making vital statistics accessible to researchers. NCI's SEER program plans to use NDI to determine deaths of all persons in the SEER registries. This should reduce the number of people lost to followup by SEER and provide better information about survival.

NDI can be easily and relatively inexpensively linked with any program or study requiring mortality data. The Index will undoubtedly increase in usefulness as it accumulates more years of mortality data.

In addition to mortality and incidence data we want to obtain information concerning factors that cause disease or increase the risk of a disease. A number of sources are helpful in this regard.

NCHS conducts several general-purpose surveys that provide statistics about the health status of the U.S. population. One of these is the Health Interview Survey (HIS) which is the principal source of information on the health of the civilian noninstitutionalized population. Initiated in 1957, interviews are conducted each week in a probability sample of households to provide data on a range of health measures, including the incidence of illness and accidental injuries, the prevalence of diseases and impairments, the extent of disability, and the use of health care services. Each year, approximately 40,000 households containing about 120,000 persons are sampled. The basic questionnaires are similar from year to year but supplemental questions may be added. In 1978 and 1979 questions on smoking were added, but these were discontinued in 1980.

NCHS is currently using HIS to conduct a pilot study on cancer costs, which may form the basis for part of a Congressionally-mandated study of the costs of environment-related health effects (Public Law 95-623).

Another NCHS survey, the Health and Nutrition Examination Survey (HANES), initiated in 1970, is the most extensive national assessment of health and nutritional status of the American people. Two surveys have been conducted, examining a total of about 40,000 people. These surveys collect data from interviews and physical examinations to estimate the prevalence of chronic diseases, establish physiological standards for various tests, determine the nutritional status of the population, and assess exposure levels to certain environmental substances. Preliminary findings from the HANES II pesticide monitoring program have found an apparent rise in tissue levels of DDT and PCBs. The implications of the observed levels are uncertain.

HANES surveys might become valuable sources of information for cancer epidemiology if sufficient resources were available. Because of its representative nature, aggregate data from the survey can be used to represent "normal" or background levels. For example, white cell count levels determined in HANES I were used for comparative purposes in an epidemiologic study of laboratory workers exposed to suspected toxic chemicals. HANES II contains certain information about dietary intake of substances which have been associated with a lower risk of cancer -- vitamins A and C -- and substances such as fats which are associated with higher risks. NCHS, with its HANES capabilities, was asked to participate in studies near Love Canal, and to evaluate the health status of certain high-risk industry groups, but was unable to do so because of limited resources.

A special HANES is now in the planning stages, which will focus on Hispanics in selected areas of the United States. The study is designed to describe the health and nutritional status of the Mexican-American, Puerto Rican-American and Cuban-American populations. Studies of such groups are necessary to acquire data in sufficient detail to describe subgroups of the population which differ from the "average."

HANES might be linked with other health data systems, such as the National Death Index, to facilitate assessment of whether particular exposure levels or certain nutritional statuses are associated with cancer mortality.

NCHS has also conducted mortality "followback" surveys, providing information on possible relations between environmental and lifestyle factors and death from cancer. Information is sought about people for whom death certificates have been filed, through inquiries addressed to those providing information for the certificate, such as the medical certifiers, funeral directors, and family members. These surveys are an efficient means to augment the routinely reported information contained in vital records. Mortality followback surveys were conducted annually in the United States from 1961 through 1968. They have since been discontinued due to inadequate resources.

Many government records, other than those maintained expressly for health purposes, may be important sources of data for researchers looking for associations between exposures and disease states. The Social Security Administration (SSA), Internal Revenue Service (IRS), Veterans' Administration (VA), the Bureau of the Census and NCHS are organizations with extensive data collections. For the most part, details about individuals are not readily available because of legal and institutional barriers, the most fundamental of which is that erected to preserve privacy and confidentiality. Restrictions have been tightened considerably in recent years by the Privacy Act of 1974 and the 1976 amendments to the Internal Revenue Code. Although health researchers have not been implicated, well-publicized breaches of confidentiality and privacy have engendered suspicion among legislators and the public about possible misuse of easily accessible files. Unfortunately, the more sophisticated and sensitive studies needed to identify many current health risks require more detailed data, which often are not available in one place. For example, to do a study relating mortality to occupational exposures, one could extract "occupation" from the IRS record, "employer" and "industry" from information collected by the SSA, and cause of death from the death certificate filed in the state in which the death occurred. (The NDI, which is described above makes it easier to locate death certificates.)

Individuals in several Government agencies have been promoting a Linked Administrative Statistical Sample (LASS), a pilot project designed to bring together records of the IRS, SSA, and NCHS. The project planners aim to provide an improved data base for mortality research by compiling statistical information from the participating agencies on a sample of individuals. The starting point will be the 1-percent "Continuous Work History Sample" of the SSA. This effort could serve as a model for future studies of cancer mortality, particularly contributions of occupational exposures.

Other linkages, and the means to accomplish them, have been suggested. One current proposal involves drawing a sample of several million individuals from those people who filled out the 1980 long census form for future matching to the NDI. This would facilitate matching cause of death with personal characteristics reported in the census. Another proposal has been made to add cause of death information to the SSA's 1-percent Continuous Work History Sample. However, since collection of cause of death data is not part of the mission of the SSA, it would presumably require money from outside SSA for implementation.

The Workgroup on Records and Privacy of the Interagency Task Force on the Health Effects of Ionizing Radiation has addressed the problems arising from the conflict between access to records for research and the right to privacy. It suggested changes in the Privacy Act, the Tax Reform Act, and commented on pending bills in 1979. The changes would have permitted access to records under tightly controlled conditions. The workgroup's report is an excellent starting point for discussion of this complicated subject and provides possible directions for Federal efforts.

As you can see a great number of data from many sources is essential if we are to understand what is happening in cancer today, and similar data are needed to aid our understanding of other chronic diseases. Much different information is needed to understand our health care system -- data on resources, manpower, and facilities, data on costs, and data on utilization. As new approaches to structuring our health care system are explored it would seem appropriate that the adequacy of our health data system be addressed.

Mr. **Walgren**. Thank you very much. We appreciate that testimony. Mr. Scheuer.

Mr. **Scheuer**. Dr. Lashof, your testimony as always is stimulating and thoughtful. Can you tell us what progress has been made or if progress has been made in the last 4 years and what trends you have seen develop since we last considered this matter.

Dr. **Lashof**. OTA has not attempted to review the activities of the Department since our report except as we have gotten into them from the current studies. It is our impression that there has been some effort to coordinate more effectively the work of the National Center for Health Statistics on utilization and hospital data with that of HCFA but this is still a major problem. They are developing a uniform hospital discharge survey, but it still needs attention. The National Center has released a number of minimum data sets. Those have been adopted by the overall Committee on Vital Statistics but have to my knowledge they have not been accepted or implemented by the Department. The cooperative health statistics system (CHSS) started off well, but I understand that a recent review carried out for NCHS has uncovered a number of problems. In the face of limited resources, I believe a decision has been made to cut back on the expectations and goals of CHSS, emphasizing the vital statistics aspect rather than some of the manpower and facility data. In that case something that we thought would become much more effective has not.

On the other hand, the National Death Index that I referred to earlier is new, and we think that it will be extremely helpful for mortality followup in longitudinal studies. The Linked Administrative Statistical Sample (LASS) that I mentioned is important as a prototype of the kind of detailed sensitive epidemiologic data resources we need if we are to understand cardiovascular disease, cancer, and other chronic diseases. The LASS project has highlighted the problems related to privacy and the release of information from various agencies. There have been some studies done on the privacy issue, and I think it could be addressed further by Congress. Resolving the problems in linking health data from these different agencies while still meeting the requirements for privacy and confidentiality would be a major step toward a good health information data system.

Mr. **Scheuer**. I would ask unanimous consent that any Members may submit questions in writing to the witnesses if they still have them.

Mr. **Walgren**. Do not feel constrained as to that 5-minute rule.

Mr. **Scheuer**. Let us do that on the second round.

Mr. **Walgren**. We will then turn to Mr. Brown.

Mr. **Brown**. Dr. Lashof, have you come across any information that enables you to determine the cost of setting up some of these data collection programs? In other words are we able to make economic judgments about the cost-effectiveness of these various systems, 169 I think you said for collecting data?

Dr. **Lashof**. I am afraid I do not have the cost data at my fingertips. There was some presented in our 1979 Federal Health Statistics report. Obviously the cost does vary with the scope and goals of each program. One of the points we tried to make in that report was that a coordinated body was needed that would set priorities and decide whether the funds were being used in the most cost-effective way possible. That body would look at the cost of each data collection system, then put these together and ask, "Is this the most logical way for this money to be spent?" Should we decide to drop some programs, do some surveys every 2 years instead of annually, for instance, to get a critical mass of money for the most important data. I think this approach still is badly needed, but since so many of the data collection systems have been set up by individual programs with no central coordination, it has not been achievable.

Mr. **Brown**. We will try and explore as we go along during these hearings the adequacy of the cost data on these various programs. Underlying my question in addition to what you have indicated is the thought that in many cases we are collecting data in the most expensive way instead of the cheapest way and if we could make large economies in a coordinated system that made use of all the available data. Of course that was to some degree the purpose of the passage of the Paper Work Act last year which dealt with the general process of collecting data from the American public. You made specific reference to the uses of the SEER program to study cancer incidence and the fact that it does not give an adequate coverage to the black population. The question I would raise is as to how much it would cost to provide adequate coverage for the black population. I think we would like to have that kind of information available in time to determine whether we ought to go ahead and do what is necessary unless it would cost a billion dollars.

Dr. **Lashof**. Dr. Gough, who has been the project director for the cancer study, I can help you on that.

Dr. **Gough**. The current SEER program costs about $10 million a year, and covers 11 geographical areas. Based on that information, I would estimate the cost of adding a new site would be about $1 million or less, but it would depend on the size of the area and the type of institutional arrangements that would be liquidated. Improved representation for blacks might require adding one area or more. Unfortunately one area with a large black population, New Orleans, is being dropped from SEER because of problems with the data they have submitted.

Mr. **Brown**. We could follow that kind of projection. You say it covers about 10 percent of the population for $10 million. That is 11 areas so we are talking about less than $1 million for each, relatively 2 million people or an area representing two million people. That kind of information is very useful. That kind of information, if it is reasonably accurate is adequate for making judgments about the economics of something like this. Let me just ask you a couple of other questions, Dr. Lashof. I have been very much concerned about the inhibitions upon the acquisition of data already acquired which you referred to in your testimony, the problems caused by the Privacy Act and the Tax Act and so on. You referred to the work done by the Interagency Task Force on the Health Effect of Ionizing Radiation which now studies that problem at considerable length. I do not have in mind exactly what they proposed. I would like to ask if the staff has access to that report and we if we know what the nature of the proposals were. If not, I would like to ask Dr. Lashof if she could provide us with a copy of it. Do we have that study of the Task Force on Ionizing Radiation.

Dr. KATZ. Yes, we do.

Mr. BROWN. Do you have any idea of why we have not taken some steps to implement some of these changes in order to facilitate a more widespread use of the data we already have? Just whatever comments you have on that. You can blame it all on Congress if you wish.

Dr. LASHOF. You know I would not do that. I guess it is hard to say why data aren't used more effectively. Some of it is just inertia, lack of enough information getting out, people being preoccupied with other things. I do not think it is a conspiracy, but it is related to the nature of data collection. Each individual group is committed around its own problem. But to really make these systems and linkages work, and to move ahead to resolve problems in coordination, it will take setting up a unit at the highest level within the Department of HHS that is committed to that goal. I suspect that other things just get in the way. The bureaucracy is big. Mike, do you have any specific comments based on the cancer assessment?

Dr. GOUGH. I have two specifics. Dr. Lashof mentioned the National Death Index. She also mentioned that mortality data are considered reliable in this country, but until the National Death Index was established if an epidemiologist wanted to follup up a group of people to find their causes of death, he had to write a letter to every State Department of Vital Statistics to ask whether or not a particular person had died in that State. Now a researcher can write a similar letter to NDI to find out if the person has died anywhere in the country, which facilitates such studies. Second the impetus for the Linked Administrative Statistical Sample which Dr. Lashof mentioned, has come mainly from people who are data system experts and not health people when they came to talk to us, asked for more involvement of epidemiologists and biostatisticians—users of the data—so that the system could be set up to be of greatest use. They are concerned with facilitating access to the data.

Mr. BROWN. How long did it take to set up the National Death Index? It would seem high priority obviously because of a data system that the country needs.

Dr. GOUGH. It was suggested by a subcommittee of the National Committee on Vital and Health Statistics in 1968. It has now begun accepting applications for use. I do not know when the efforts to set up the index began.

Mr. BROWN. That is relatively fast action.

Dr. LASHOF. Yes.

Mr. BROWN. It is only 7 years perhaps more, like 13 more or less. The Congress has been expressing its views on the need for the type of improved health statistics for a number of years and one of the mechanisms set up was the National Committee on Vital and Health Statistics which has a charge under the law to not only make an annual report on health based on the statistics but to make proposals for improvement in the health statistics systems. I am not familiar with the committee or the work it has done and I want to ask you for whatever it is worth if the committee has been functioning and has been making recommendations in accordance with the mandate of the law to achieve some of these changes that you are suggesting in your statement, Dr. Lashof.

Dr. LASHOF. I believe the committee has been functioning Congressman Brown. I really cannot comment on how many recommendations have been made, what has happened to those recommendations, other than the National Death Index, which Dr. Gough just mentioned. I suspect that questions should be directed to the Department, and I believe you do have the chairman of the committee scheduled to testify later this week. OTA met with the committee when we had completed the Federal Health Statistics Report. We briefed them and they seemed very interested in it. I believe they have continued to make recommendations, but they are not implementers.

Mr. BROWN. I will ask that question of a number of witnesses because I think we have a classic case here of where there is not any need for new legislation. We have plenty of legislation on the books, yet we still do not have the system that would seem to fulfill the mandate of the legislation. I am interested in trying to find out just what we need to do in order to do that. I suspect I know one answer and that is provide more money but if my preliminary feeling is correct that we could save a lot of money by doing this thing properly then the question of putting more money into it is not the fundamental question. The fundamental question is organizing the system.

Dr. LASHOF. I think the fundamental issue is the development of a coordinated mechanism a framework and sets the priorities for the data and moves in a much more coordinated way rather than letting each agency continue to collect what it thinks it needs or wants for its specific mandate.

Mr. BROWN. Thank you. I do not have any more questions.

Mr. WALGREN. Mr. Shamansky.

Mr. SHAMANSKY. Thank you, Mr. Chairman. Just two aspects. Getting back to something Congressman Brown first mentioned with respect to the black population not being in this original SEER program particularly. I am curious as to why not. If you are going to cover 10 percent of the population how could you miss 10 percent of the American population?

Mr. GOUGH. I think this deserves a somewhat fuller explanation. NCI had several criteria for inclusion of areas in SEER. Sites were chosen on the basis of unique subgroups in their populations, and also, of necessity, for their demonstrated ability to operate a cancer reporting system. This limited the choices. Thus, for the eleven present areas, while 10 percent of the overall population is represented, only 9 percent of the black population is covered. Two areas with large black populations were added after the program began, so data for the first couple of years is not available from them.

Ideally, we probably want overrepresentation of blacks in the areas covered to assure reliable rates. Reliability, in this case, is related to numbers of people covered, rather than exact proportional representation. The larger the numbers, the greater the reliability. Thus, for the black population, we may need more than 10 percent of the SEER sample to achieve an acceptable level of reliability.

Mr. **Shamansky**. But there was no recognition that a large population subject apparently to high incidence of cancer——

Dr. **Gough**. I think there is recognition of the fact blacks were underrepresented but it was not corrected when the SEER program was established. It has been a matter of concern to NCI.

Mr. **Shamansky**. What do they do about it?

Dr. **Gough**. I think in this case they asked for more money to establish new reporting areas.

Mr. **Shamansky**. We already had opinions expressed that maybe they could take the initiative with the money they have.

As a business lawyer in my real life as distinguished from this new congressional life of mine many of our clients complain about the duplication of information that they have to give to each different agency. I have always asked myself why do we have to give the same information to several different outfits. Why could that not be pooled. But in the health areas you cannot get a linkage up of the various data collectors. Is this basically a parochial bureaucratic institutional bias built into every agency? Is that basically what you are telling me?

Dr. **Lashof**. That is probably close but I think that probably oversimplifies it, in all fairness.

Mr. **Shamansky**. How could we get this more complicated?

Dr. **Lashof**. More complicated?

Mr. **Shamansky**. You said it was oversimplified.

Dr. **Lashof**. The answer, OK. I am not in DHHS anymore but I was there once and I was a State health officer once. Let me draw from that past experience. I think part of the problem is that the agencies have different specific mandates and they need data to fulfill those mandates. Some of the data, indeed, is the same, but some of it is unique and they have found trying to share data or trying to get somebody else to collect data for their particular needs an extremely difficult problem. First of all, the one who controls and pays the bill has more authority over what gets done and more ability to supervise the accuracy. So part of it is a lack of trust in someone else to collect data for you. If you are responsible for this program you want to collect your own data and you need it in one form and you do not accept the way somebody else has collected it for something else. I know there has been discussions back and forth between the National Center for Health Statistics and the Health Care Financing Agency on the uniform hospital discharge study for at least 4 or 5 years, and they just do not seem to be able to agree what basic data each of them needs.

Mr. **Shamansky**. That to me is incredible.

Dr. **Lashof**. You will have to address that question to them.

Mr. **Shamansky**. I understand that is not your territory or responsibility. We have established that. But the question is based on your experience—you know the old bias, is it for Congress then to tell the various bureaucracies there will be a national component and you will do certain things or you do not get the money?

Dr. **Lashof**. That is one alternative. I guess you would have to look at what the implications would be if you came down that hard. I guess that is one way to approach it.

Mr. **Shamansky**. Thank you, Mr. Chairman.

Mr. **Walgren**. Mr. Skeen.

Mr. SKEEN. Thank you. Doctor, I would like to continue with some of the leads that have been given by Mr. Shamansky and Mr. Brown. It seems to me that in Government we mandate a lot of data collection with the best of intentions, but where we go astray is when no one ever seems to collate or summarize or come to any conclusions with the information. Do you think the medical community might not trust this information because it is Government collected? Is this your perception, that they might argue with the methodology of how the data is collected and what it is used for? Is that an accurate portrayal of part of the problem?

Dr. LASHOF. In part, but I think that might be a little overstated. Accuracy of data is always an issue. Certainly in health, it is difficult to be sure about recorded data—even, for example, cause of death, specific diagnoses whether the details of the primary cause of death versus secondary causes are correct. There are continuing efforts to educate hospitals, coroners and physicians about filling out death certificates accurately, and on the whole I think our vital statistics data have been steadily improving. In a specific program, like SEER, one can train the data collectors more intensively to make sure data are accurate but even then it is not easy. Moreover, in any data collection system, if someone does not like the results of the data, it is often easy to attack the data in an effort to discredit the results; sometimes that is valid and sometimes not.

Mr. SKEEN. So it is extremely difficult to standardize the data collection process?

Dr. LASHOF. I think so.

Mr. SKEEN. Let me ask one other question. I was interested in why the New Orleans collection project was shut down. It was passed over because it evidently involved a large population of blacks and I think this is one of the omissions. It seemed to be the only major data base from a black population. I would be interested in why it was shut down.

Dr. GOUGH. No, sir. That is a question that NCI could answer better than I. My understanding is that somewhere in the process of registering cases of cancer and communicating that data to NCI, New Orleans was not up to the standards that the SEER program required, by contract.

Mr. SKEEN. What you are saying is that they did not conform within what would be called standardization. I am not asking you to accuse them; give me your own opinion.

Dr. GOUGH. They were not doing something up to par. That is my understanding.

Mr. WALGREN. Mr. Gregg.

Mr. GREGG. Do you assign priority to what you think should be undertaken given a limited amount of money?

Dr. LASHOF. I do not think I really could do justice to that kind of a question. First, we as an office have not looked at the collection of data since 1979. Even then, we did not look at it in that way. I think what you suggest would be a very time consuming analysis that the Department would have to undertake. However, I think in the cancer area we have some feelings about the top priorities for data collection. Expansion of the SEER program is one. Further work on record linkages is certainly another.

Dr. GOUGH. There are some other fairly simple things that could be done. For instance, one of the great concerns is whether or not occupation contributes to early death and morbidity. On the death certificate there is space for the usual occupation and industry of the decedent.

Those items often are not completed, and even when they are, there are doubts about their accuracy. In any case, they are not routinely coded, and therefore never become available as aggregate statistics. Having these statistics might help to stimulate new hypothesis about occupational causes of cancer.

Dr. LASHOF. If I tried to look at it broadly, two priorities stand out. Certainly, a cooperative health statistics system going, which has been a longstanding goal, is of great importance. As I mentioned before, the CHSS has been scaled down because of the resource problems. Second is the need for good data linkages so we can do long-term studies looking at factors such as occupation, diet history, and so forth. These are the big things in the area of chronic diseases.

With regard to priorities for the health care system, I think the uniform hospital discharge survey and implementation of the minimum data set that the center developed last year would probably run quite high.

Those are the ones that come to mind.

Mr. GREGG. Obviously you haven't as many dollars as you want, so you have to set priorities.

Dr. LASHOF. As I say, I haven't had that responsibility, so I haven't tried to look at that. I think that is the first chore that the Department has to do in setting up a coordinated system. What has been lacking is one central body at the secretarial level to look at the totality of data collected and beginning to set better priorities for spending money.

Mr. GREGG. Who is doing that?

Dr. LASHOF. That should be done by the Department of Health and Human Services.

Mr. WALGREN. Will the gentleman yield?

Mr. GREGG. I would be happy to yield.

Mr. WALGREN. It is my understanding that there is Public Law 95-623 which vests in the Secretary of Health and Human Services the responsibility to focus and review the quality and quantity of the data collected with respect to cancer. I gather the Secretary level has not given much attention to that.

Has the Department responded to the mandate that is apparently in that law?

Dr. LASHOF. Are you referring to the mandate that the Department do a study of the costs of environment-related health effects? Public Law 95-623, did you say?

Mr. WALGREN. I am referring to 623, but I was under the impression that that sort of mandated the Secretary to coordinate or certainly create a coordinated judgment about the value of the data collected so that we won't have an uncoordinated effort.

Mr. SCHEUER. Will the gentleman yield?

Mr. WALGREN. I am happy to yield.

Mr. SCHEUER. Did not 623 also mandate the Secretary to set up a system for collection of standardized health statistics?

Dr. Lashof. I do not remember. I would have to look in my directory.

Mr. Walgren. Have you experienced that level of attention by the Secretary?

Dr. Lashof. I was only in the Department of HHS 1 year, 3 years ago, so I think that is a hard question for me to respond to. I am afraid that has to be directed to the Department.

Mr. Walgren. If the gentleman would continue to yield, I would like to get one other estimate.

When you talk about the limited dollars and the need to do more with less dollars, the dollars must break down into two components: One, gathering the data; and the other, crunching the data.

Take the cancer program, particularly: How much of the money is spent in gathering the data and what is the measure of our effort after the data comes in to make the data work for us, in dollars, and overall?

Dr. Gough. I do not know the answer to that.

Mr. Walgren. Can you give me an estimate? I and other members, I am sure, don't have anyway of really understanding whether an adequate effort is being given to analyze the data. I can understand some circumstances where there would be bureaucratic inertia to go out and collect very broadly but not analyzed properly.

Dr. Gough. NCI is analyzing and publishing an analysis on a yearly basis.

Mr. Walgren. Thank you, Mr. Gregg.

Mr. Gregg. Following up on this issue of the responsibility of HHS, don't you know what they are doing over there?

Dr. Lashof. Well, not really. The Office of Technology Assessment does not try to monitor the departments. We carry out specific studies at the request of Congress. We did one on Federal health statistics in 1978, published in 1979. We have completed one on cancer, which contains a section on cancer data, but we are not an oversight agency and we don't try to keep on top of what they are doing.

We only respond to the requests of Congress to carry out specific studies. GAO may be able to answer some of the other questions.

Mr. Gregg. They will input how you spend the money; is that correct, with regard to priorities?

Dr. Lashof. No, not us. The Office of Technology Assessment is an arm of Congress.

Mr. Gregg. Perhaps I misunderstood what you were saying.

Dr. Lashof. The prioritizing for data collection would be set by HHS. We are not data collectors in the Office of Technology Assessment.

Mr. Gregg. In spending your money, how are you going to set your priorities?

Dr. Lashof. By the requests Congress makes to us. We are not data collectors.

Mr. Gregg. What would you believe to be the best way we could spend that money were you to set priorities for yourself?

Dr. Lashof. We are having a little bit of a problem in understanding the role of our office. Our office has nine different programs in different areas ranging from health to international security, water, and so on. We are governed by a congressional board and we do studies in response to requests from chairmen of committees.

The priorities of the Office of Technology Assessment are set by a congressional board that looks at the requests that come to our office from different committees. We develop budgets for them. We present them to our board and say, "Shall we do this?" We then carry out studies along the lines we are asked to do, but we are not data collectors.

Mr. GREGG. I understand that now, and I thank you for the clarification.

My question, though, is, In setting priorities for funding, where do we put the money? In what areas do we want to do data collection with regard to developing coordinated health information?

Dr. LASHOF. That is a good question, but OTA has not studied that for the Congress specifically. That question would have to be more specifically answered by DHHS.

What I did indicate is, from the studies we have done dealing with statistics—our cancer study and our Federal health statistics study—that one would want to take a good look at the cooperative health statistics system and at the linkages, and at developing uniform data sets. Those would be three priorities we would think Congress would want to address.

Mr. GREGG. You also mentioned hospital discharge.

Dr. LASHOF. Yes.

Mr. GREGG. What sort of resistance do you run into from the hospital community for a standard discharge form?

Dr. LASHOF. That is a question for the Department.

Mr. GREGG. What do you anticipate?

Dr. LASHOF. If I wear my old hat, when I was State health officer, the biggest problems we ran into came from the multitude of types of data that were necessary for the different accrediting bodies—medicare, medicaid, and so on. I don't think the hospitals resisted the idea of a uniform data system. I think they accepted that.

The problems came with the different agencies wanting different information. The problem has been more at the level of getting agreement on what is a uniform data set rather than resistance from the hospitals. I haven't looked at that problem myself in over 4 years.

Mr. GREGG. Thank you.

Mr. WALGREN. Thank you very much, Doctor.

Mr. Brown?

Mr. BROWN. Could I ask unanimous consent that Dr. Lashof's statement before the Senate Labor and Human Resources Committee on April 1 be included in your record also? I think she addresses a number of questions we are interested in.

Mr. WALGREN. Without objection.

[See p. 30.]

Mr. BROWN. Could I also ask that report of the task force on ionizing and radiation, as it relates to privacy of data, be made a part of the record, since it was referred to?

Mr. WALGREN. Without objection.

[See p. 63.]

Mr. **Walgren**. We would like to leave open the possibility of submitting some questions to here for response in writing that would also be made a part of the record.

Dr. **Lashof**. We would be pleased to provide those things.

Mr. **Walgren**. Since the question has come up about the Secretary of Health and Human Services actions thus far, on behalf of the committee, we want to express regret that the Department of Health and Human Services did not provide a witness at the outset today that would have been able to give us an overview of the current health data selection activities and to answer questions in that regard.

The Department did send some material for an overview that is in our folders and that will be made a part of the record.

In addition, Dr. Lashof was able to volunteer some view of the Department's activities in view of her past involvement.

In addition to the materials provided by HHS, the Institute of Medicine is also providing a statement for the record regarding their most recent study of this area, and I would ask unanimous consent that this supplementary material be accepted and included in the record. Without objection, that will be made part of the record at this point.

[The information follows:]

STATEMENT OF

JOYCE C. LASHOF, M.D., ASSISTANT DIRECTOR
OFFICE OF TECHNOLOGY ASSESSMENT
CONGRESS OF THE UNITED STATES

BEFORE THE
COMMITTEE ON LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

APRIL 1, 1981

Mr. Chairman and Members of the Committee:

I am Dr. Joyce C. Lashof, Assistant Director of the Office of Technology Assessment. Accompanying me are Dr. H. David Banta, Health Program Manager and Dr. Bryan R. Luce, Senior Analyst in the Health Program. We are pleased to appear before you to describe the National Centers for Health Statistics, Health Services Research and Health Care Technology. OTA's interest in these Centers is long standing and in one way or another the Centers have been discussed in many of our previous studies. The functions of the National Center for Health Care Technology is addressed in our current study, "Strategies for Medical Technology Assessment." A staff paper detailing the history and functions of this Center has been delivered to the Committee.

The three Centers are related not only organizationally, but also substantively. Yet, each Center has its own unique missions, and activities of one overlap relatively little with activities of another.

The Office of Health Research, Statistics, and Technology (OHRST) of the Public Health Service was created as part of an executive reorganization in January 1979. It has responsibility for the National Center for Health Statistics (NCHS), the National Center for Health Services Research (NCHSR), and the National Center for Health Care Technology (NCHCT). Formerly the Office of Health Policy, Research, and Statistics (OHPRS), OHRST was established to strengthen the relationship between health technology assessment, health statistics, and health services research.

The National Center for Health Statistics (NCHS) is the only federal agency established specifically to collect and disseminate data on the health of the American people. Congress first authorized a continuing survey and special studies of sickness and disability in the National Health Survey Act of 1956, Public Law 84-652. In 1960, the National Health Survey merged with the National

Office of Vital Statistics, which was established in 1946, to form NCHS. Since that time, NCHS has played a major role in the development of national health statistics policy and programs. Organizationally, the Center has moved several times within PHS; it is now located in OHRST.

The Health Services Research, Health Statistics, and Medical Libraries Act of 1974, Public Law 93-353, established NCHS statutorily and expanded its responsibilities. The law both listed the categories of general-purpose statistics to be collected by NCHS and mandated that a detailed report analyzing the country's health care costs and financing, health resources, health resource utilization, and health status be submitted annually to the President and Congress.

To fulfill its mission, NCHS conducts a number of data activities that provide vital statistics and health facility, health manpower, and health status and health care utilization statistics. NCHS also has the primary administrative responsibility for the Cooperative Health Statistics System (CHSS), a joint Federal, State, and local program for the collection of health data.

The NCHS Division of Vital Statistics collects natality, mortality, marriage, and divorce statistics. These statistics are derived either from microfilm copies of State certificates of marriage and divorce and State records of births and deaths, or from the computer tapes supplied through the vital statistics component of the CHSS program. NCHS then publishes statistical summaries based on this State-supplied information. In addition, NCHS periodically conducts "followback" surveys that are based on samples of birth or death records. They are designed both to provide national estimates for a range of items that are not usually included in vital records, such as demographic characteristics, and to evaluate the quality of data contained in the vital records.

The NCHS Master Facility Inventory, initiated in 1962 and updated biennially, furnishes information on all inpatient health facilities that provide medical, nursing, personal, or custodial care. Data are collected on facility ownership, finances, patient population, provision of services, number of beds, and patterns of staffing. Another facility inventory, also updated biennially, supplies information regarding family planning clinics. A third example of a facility data system is the National Nursing Home Survey. Conducted every two years, it gathers data from a sample of nursing homes, their residents, and their staff.

NCHS manpower statistics consist of periodic inventories of various health professionals, including physicians, registered nurses, pharmacists, and optometrists. The manpower inventories are conducted only in States that have not implemented the CHSS program. In 1975 and 1976, for example, NCHS conducted a survey of hospital staff. This survey covered 110 health occupations and was used both to identify manpower shortages or oversupply and to assess trends in the recruitment and the employment of allied health personnel.

NCHS also operates five major general-purpose surveys that provide statistics on the health status of the U.S. population and on their use of health care services. The Health Interview Survey (HIS), performed annually since 1957, provides data on the incidence of illness and accidental injuries, the prevalence of diseases and impairments, the extent of disability, the utilization of hospitals and other health care services, and other health-related topics. These data are obtained through interviews conducted in a probability sample of households.

The Health and Nutrition Examination Survey (HANES), which was initiated in 1971, obtains standardized data from direct physical examinations of a sample of the U.S. population. Data are collected periodically to estimate the prevalence of chronic diseases, to establish physiological standards for various tests, to determine the nutritional status of the population, and to assess exposure levels to certain environmental substances. Data are also collected, through interviews, on self-perceived health needs and health practices. The National Survey of Family Growth acquires data on childbearing and family growth patterns. These data are needed to interpret current trends in the birth rate, to aid in the planning, management, and evaluation of family planning programs, and to provide guidance for efforts in the areas of infant and maternal health. Data are collected through personal interviews with women of childbearing age. NCHS began this survey in 1973.

The Hospital Discharge Survey (HDS), begun in 1965, collects data from the medical records of a sample of patients discharged from a number of the Nation's short-stay hospitals. Data abstracted from patients' medical records include demographic characteristics, diagnoses, surgical procedures, and administrative information about the hospital stay. Annual profiles on national and regional hospital use, organized according to diagnoses, procedure, patient characteristics, and other variables, are then published by NCHS. The National Ambulatory Medical Care Survey (NAMCS), first conducted in 1973, gathers data on a number of patient visits from a probability sample of office-based physicians. Participating physicians complete a brief encounter form that requests information regarding patient characteristics, reason for visit, diagnoses, treatment and services, and disposition.

In FY 1980, Congress appropriated $40.2 million for all program operations, most of which went for the Center's survey activities, and $3.1 million for program support. The present administration's budgets for both fiscal years 1981 and 1982 slightly increase program support to $3.2 and $3.4 million, respectively, but substantially decrease program operations to approximately $35.5 million annually.

In June of 1979, OTA prepared a report for Congress titled Selective Topics in Federal Health Statistics in which OTA described the increase and fragmentation of federal efforts to collect health-related data. That report noted that in addition to the statistical activities of the NCHS, numerous programs in the PHS and HCFA collect data to meet program-specific needs. Further, seven agencies and departments outside of HHS also conduct major health statistical activities in pursuit of their missions. Because this growth in federal health data efforts has occurred primarily outside agencies with major statistical responsibilities, there is a lack of a coherent system to organize and manage the increasing numbers of assorted data collection projects.

In the report, OTA suggested to Congress that there was a need to assign formal responsibility for the functions related to the coordination and planning of federal health statistics to a central coordinating body within HHS. Such a unit should have sufficient authority to impose decisions on agencies and offices in the Department, the necessary statistical and analytical capabilities to conduct activities requiring technical expertise, and adequate resources to build a viable core effort. The coordinating unit should perform three essential functions: developing an analytical framework for planning the statistical system, improving the efficiency of data collection activities, and ensuring data accessibility for potential users. That need has not changed.

Finally, OTA noted that a number of offices within HHS could assume responsibility for comprehensively supervising federal health statistics. Different offices could be accountable for activities requiring authority over substantive program agencies and for activities requiring technical capabilities. But, the fundamental requirement in assigning responsibility is an unambiguous mandate to manage health statistics. NCHS is the logical agency to coordinate activities requiring technical capabilities. Other activities such as setting policy of data collection could be elsewhere.

The second Center that I wish to discuss is the National Center for Health

Services Research (NCHSR). During the last two decades, the field of health services research has emerged from a fragmented array of research efforts into a multi-discipline approach to study major health care organizational issues. Health services research was initially supported by several different agencies of the PHS. Growing governmental and public awareness of the need for increased understanding of the workings of the health system led to recommendations by the White House Conference on Health in 1965 and by the President, in his message to Congress on health and education in February 1967, for the formation of a national center for such research.

Although NCHSR was created in 1968 without explicit Congressional authorization, it was not until 1974 that NCHSR received legislative authority via the Health Services Research, Health Statistics, and Medical Libraries Act; the same Act, noted above, which established NCHS statutorily. Since then, several laws have added or modified NCHSR's research domain.

NCHSR has three principal responsibilities: to develop information that might be used by various decision makers in the public and private sectors; to serve as the focal point for coordination of health services research within the Public Health Service; and to ensure that results from the research, evaluation, and demonstration activities of NCHSR are disseminated rapidly and in a form that is usable.

NCHSR is the major supporter of general purpose, independent, and broadly focused health services research. Its budget has steadily decreased from a high of $65.4 million in 1973 to its fiscal year 1981 operating budget of $23.3 million. NCHSR is not responsible for the administration of any health care delivery or reimbursement activities; it exists solely to conduct and sponsor health services research and to disseminate the results of that research to relevant governmental agencies, the research community, and other interested parties. The NCHSR's statute language is very broad which allows it considerable leeway in its selection of specific research issues to pursue.

Specifically, NCHSR undertakes and supports projects organized around ten issue-based areas or catagories of research: health promotion and disease prevention; health care and the disadvantaged; health care costs and expenditures; health insurance; health manpower; health planning and regulation; technology and computer science applications to health care; quality of care; emergency medical services; and long-term care. An eleventh category, called special studies, is comprised of research projects that examine methodological issues and problems in the conduct of health services research.

NCHSR's health services research efforts are allocated among intramural research, extramural research grants and contracts, and center grants. Intramural research is subject to an informal review process within NCHSR. To screen and select grant and contract applications which it receives, NCHSR employs a dual review type of evaluation process quite similar to the peer review system of the NIH and the NCHCT.

The NCHSR authorizing legislation requires that at least 20 percent of its research budget be used for intramural research. The total research budget for FY 1980 was $19.45 million; $3.89 million was used to support intramural research and $12.37 million was used for extramural research, demonstrations, and evaluations.

NCHSR is also charged with disseminating health services research information. Toward this end, the Research Center has supported an active dissemination program in an effort to provide effective and timely findings of research by means of publications, press releases, conferences, and workshops.

The House Conference Report of the 1978 Health Services Research, Health Statistics, and Health Care Technology Act expressed the wish to make clear that Congress did not intend the NCHSR to compete with the new NCHCT in conducting assessments, research, evaluations, and demonstrations respecting the efficacy, safety, effectiveness, cost-effectiveness, and social, ethical, and economic impacts of health care technologies. Rather, it intended to "make certain that the National Center for Health Services Research can continue to undertake and support development programs concerning new technologies directly relevant to the organization and delivery of health care services." For instance, research conducted with respect to uses of computer science and health services delivery and medical information systems was to be maintained by the NCHSR. Finally, the conferees recognized that "distinguishing the precise boundaries of the NCHSR and the National Center for Health Care Technology may be difficult in some situations and (we) expect the two centers to work together to minimize duplication of effort."

While NCHSR had undertaken technology assessment activities on a somewhat broader scale before the 1978 legislation, the bulk of its resources in technology areas has traditionally focused on computer science in health services delivery and medical information systems. As a result, the NCHSR technology assessment role has not had to change significantly since the inception of NCHCT.

Examples of NCHSR's technology and related research are three broad computer technology areas: hospital information systems, automated ambulatory records systems, and clinical data banks. Long-term investments by NCHSR in technology and computer science applications includes the development of Automated Hospital Information Systems (AHIS); the design and application of the Problem Orientation Medical Information System (PROMIS) as a source of medical guidance and consultation for the physician; the development of the Computer Stored Ambulatory Medical Record (COSTAR), currently being deployed by the San Diego County Health Department in all public clinics; and the establishment of clinical data banks for chronic coronary artery disease and rheumatic disease in order to make available aggregated clinical experience for the improvement in clinical management of the patient and for the assessment of new medical technologies. During 1981-1982, NCHSR intends to continue to support these areas, as well as to give attention to analysis of the various organizational and economic issues involved in the transfer and adoption of information technology.

In 1978, the House Committee on Interstate and Foreign Commerce expressed the view that "the budget of the NCHSR has been wholly inadequate over the past 5 years." Nonetheless, the precipitous drop of the budget has continued unabated. This seems unfortunate since NCHSR is the only focal point that the federal government has to study and solve the issues related to the delivery of health care, including the way in which the system is organized and financed. In addition, this Center funds most of the nation's research on quality of care. The results of its research activities have been instrumental in the development of peer review and medical audit techniques, and various health care delivery options, as well as innovative incentive financing arrangements such as the HCFA and New Jersey experiment to pay for hospital care on a case-related basis.

Passage of P.L. 95-623 (the Health Services Research, Health Statistics, and Health Care Technology Act of 1978) created a more visible nucleus of federal involvement in medical technology assessment: The National Center for Health Care Technology (NCHCT). In January 1979, the Secretary of HHS joined NCHCT with the NCHS and NCHSR in a new Office of Health Research, Statistics, and Technology (OHRST) within the Office of the Assistant Secretary for Health. It is important to note that the law permits the Secretary to locate the Technology Center anywhere under the jurisdiction of the Assistant Secretary for Health. The law also authorized the establishment of the National Council on Health Care Technology, which fulfills a number of advisory functions in conjunction with the programs of the NCHCT.

The major issues that gave rise to the creation of the NCHCT related to the safety and effectiveness, appropriate use, and cost of new and existing health care technologies, and the impact of technology on the individual and society. As the number of health care technologies and the complexity of the issues surrounding their appropriate use have increased in recent years, so too has concern about the limitations (or lack) of information for decisionmaking by the public and private sectors on the use of and payment for technologies. The law mandated the Center to undertake and support a variety of programmatic activities directed at improving the understanding of the issues and consequences associated with the development and application of technology in health care. The law defined "health care technology" broadly to include: "Any discrete and identifiable regimen or modality used to diagnose and treat illness, prevent disease, maintain patient well-being, or facilitate the provision of health care services."

The primary functions of the Technology Center are to conduct research on issues pertaining to health care technology, sponsor and coordinate assessments of high-priority emerging, new, and established health care technologies, and to communicate the results of its research and assessments to a broad range of groups in both the private and public sectors. The Technology Center does not have the authority to regulate the utilization of health care technologies, nor are its activities aimed at determining or interfering with the practice of medicine. Also, the Center has no direct cost containment responsibilities. Rather, its function is to undertake, support and synthesize research and assessments of technology to offer providers, consumers, industry and governmental agencies reliable information on which to base their decisions.

The Technology Center's assessment activities fall into two main categories:

1) Full assessments of technologies (i.e., extensive, integrated analysis of the safety, efficacy, effectiveness, and social, ethical, and economic implications of a specific technology) are identified by the Technology Center through the Secretary, the Council, the Surgeon

General, or others as being a high priority. In consultation with the advisory bodies, the Technology Center has developed a tentative technology assessment plan that sets forth the health care technologies to which it will devote attention during the next few years. Under the plan, NCHCT would have primary responsibility for undertaking full assessments of these technologies. The Center would also complement or co-sponsor assessments with other federal agencies, such as the NIH, the CDC, and and the FDA, on specific technologies that present issues of mutual interest and concern.

2) "Focused" assessments address one or more but not all aspects of a technology. When issues are clarified through full assessment and other means (e.g., new research), the Center supports or performs assessments of specific aspects of technologies through its extramural and intramural research programs, respectively. In June 1980, the NCHCT published its first public solicitation for research grant applications, and has already awarded several grants this fiscal year. The Center is now initiating its intramural research program; early efforts included preliminary analysis of the cost-effectiveness of several technologies including liver transplants, positron emission transaxial tomography (PETT), and heart transplants.

Further, the law states that NCHCT "may make recommendations to the Secretary respecting health care technology issues in the administration of laws under the Secretary's jurisdiction, including recommendations with respect to reimbursement policy." The Technology Center serves currently as the focal point within the PHS for the provision of scientific and medical advice to HCFA on Medicare coverage issues. These issues are questions raised by HCFA regarding the safety and efficacy of particular medical items, procedures, or services. HCFA uses this advice in reaching its decision on Medicare coverage policy and in developing reimbursement instructions for Medicare carriers and fiscal intermediaries. The NCHCT inherited a backlog of 58 requests from the HCFA when it began operations in 1979, and has since chipped away at the inventory of outstanding issues. The backlog has been reduced to 9 issues at present. Another 49 new issues have surfaced during the short course of the Center's history, and only 26 of these remain to be evaluated. In addition, new requests have been received at an increasing frequency of one or two per week. Thus, HCFA appears to be increasingly relying upon NCHCT's advice.

Other assessment activities carried out by the Technology Center include: a) the compilation, as required by law, of an annual listing of health care technologies that are under development and appear likely to be used in the practice of medicine; and b) an innovative interorganizational effort with public and private third party payors to develop a mechanism which would be aimed at collecting clinical data about certain selected new technologies as they begin to diffuse in the practicing area. It is expected that this will allow more definitive conclusions to be drawn at an earlier time about the safety, efficacy, cost, and utilization of particular technologies, and also allow a more orderly progression of some technologies from limited experimental usage to widespread clinical application.

The NCHCT has a broad mandate to communicate and disseminate the results of its assessments and research for use by health care providers; the academic community; Federal agencies and other organizations that have health delivery, health planning, reimbursement, regulatory, or related responsibilities; consumers; industry; the Congress; the public; and, others. The Center disseminates information by means of press releases; NCHCT publications; articles in scientific and medical journals; Government informational services, such as those of the National Library of Medicine, National Institutes of Health, and of the Food and Drug Administration; Professional Standards Review Organizations

(PSROs); health systems agencies (HSAs); professional and voluntary organizations; and, meetings and conferences held by the Center and various professional, governmental, and other groups.

Within the DHHS. the NCHCT is the focal point for coordinating Departmental activities pertaining to health care technology and its assessment. The principal mechanism for achieving this coordination is the DHHS Technology Coordinating Committee (TCC), which includes representatives from all PHS agencies, the Health Care Financing Administration (HCFA), and other Federal departments, agencies, and offices with interests in health care technology. The TCC has been instrumental in surfacing technology issues of overlapping concern and in need of more in-depth assessment.

Despite widely-publicized concern about the costs and effectiveness of medical technology, the Technology Center received no appropriations in its initial six months, and only $3.25 million in 1980. $4.75 million was proposed for 1981 (later cut back to $4.0 million). The Center's austere budget history has served to curtail its latitude thus far in several areas; for example:

- the staff is heavily augmented by part-time people, temporary appointments, and special program appointments;
- the extramural research centers (required by law, to the extent practicable, to be operational by September 1, 1981) have not been established, and are currently in what has been described as the "hold phase;" and
- the research training program is in the same predicament.

In general, the legislative mandate of NCHCT has far exceeded the appropriations necessary to carry it out.

In summary, Mr. Chairman, the three National Centers which I have discussed this morning have quite different mandates. The National Center for Health Statistics provides much of the base-line data upon which the research efforts of the other Centers, NIH, and most of the nation's other health researchers rely. The National Center for Health Services Research either sponsors or conducts most of the nation's research on the health care delivery system. The National Center for Health Care Technology is the newest of the Centers and is just beginning to establish a track record upon which it can be evaluated. It is charged with identifying those health care technologies which require assessment, coordinating federal assessment activities, conducting and supporting assessments where appropriate, and advising the Health Care Financing Administration as requested.

Thank you for inviting us, Mr. Chairman. We will be happy to try to answer questions.

6/2/81

DEPARTMENT OF HEALTH & HUMAN SERVICES
Office of the Secretary
Washington, D.C. 20201

DEPARTMENT OF HEALTH AND HUMAN SERVICES

BRIEFING MATERIALS ON
DEPARTMENTAL ACTIVITIES IN THE AREA OF
HEALTH INFORMATION AND STATISTICS

Prepared for

THE HOUSE SCIENCE AND TECHNOLOGY COMMITTEE
SUBCOMMITTEE ON SCIENCE, RESEARCH AND TECHNOLOGY

AND

SUBCOMMITTEE ON NATURAL RESOURCES, AGRICULTURE
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OVERVIEW: NEED FOR HEALTH INFORMATION AND STATISTICS

The Department of Health and Human Services recognizes that a comprehensive information base is an essential resource in health planning and policy formulation and in program management and evaluation. Timely and reliable data are needed on the health status of the population, the availability of health resources, the accessibility and use of services, the costs of services and resources, sources of funding and the quality and outcome of care rendered.

In recent years, informational needs of health-related governmental agencies and non-governmental organizations have accelerated as a result of increasing health care costs, the need for systematic planning of health resources' availability and use, and the emergence of new programs to measure and improve quality of care.

One of the significant challenges in the field of health statistics today, continues to be the development of coordinated and responsible health data systems capable of satisfying the multiple needs for data at the State and substate levels and for providing the data needed for national health policy-making as well as evaluation of the impact of Federal programs.

The increasing need for quantitative information coincides with increasing limitations on financial and personnel resources available to meet such demands and increasing public concern about the burden Federal reporting requirements place on the respondent. Consequently, effective planning for statistical activities, including the setting of priorities, coordination, and elimination of unnecessary reporting burden on the public continues to be critical.

HEALTH DATA ADVISORY COMMITTEE (HDAC)

The Health Data Advisory Committee was established in February 1979 to advise the Secretary on current and long-term health data needs for planning and arrangemen, on policies and procedures for Department-wide corrdination of health statistics activities, on proposals for major new health statistics systems and on minimum basic data sets.

The Committee serves as a vehicle for a Departmental level, coordinated approach to data oriented heatlh policy issues. It provides an internal forum for discussing and resolving specific issues and a locus within the Department for liaison and cooperative arrangements with other agencies. Active participation of representatives for the Office of Federal Statistical Policy and Standards (OFSPS), the Department of Defense, and the Veterans Administration provides the Department with valuable information on the relatd experience and data requirements outside the Department.

THE DEPARTMENT'S STATISTICAL PLANNING PROCESS

Goals and Objectives:

The goal of the Department's health statistical planning effort is a national health information system whose purpose is the formal organization of concepts, methods, manpower, equipment and other resources for acquiring and analyzing the data needed for policy formulation, planning, program management, evaluation, research, monitoring and other purposes. The system includes both general purpose and program specific data activities.

The Health Statistics Plan attempts to provide a conceptual and organizational framework for the health statistics activities of the Department, to describe current and planned activities, and to identify problems evident in the existing activities and arrangements which comprise the current health data system of the Department.

The major goal of the Department's health statistics planning continues to be the development of coordinated health data systems that will:

- meet statistical needs for developing and evaluating national health policy;
- meet program management data needs for health programs of the Department;
- respond to Federal, State, local, and private needs for health statistics in a timely fashion;
- assure confidentiality of data and privacy of respondents to Federal health data collection activities while assuring availability of appropriate information to the public;
- assure quality and accuracy of statistics;
- assure compatibility of statistics across the major Departmental data collection programs through standards where possible and promote record linkage among data files to enhance comparability and usefulness of data resources; and
- assure maximum compatibility of statistics with major international, national, State and local heath statistics systems.

The Planning Process:

The health statistics planning process and the preparation of the Departmental Health Statistics Plan follows an approach consisting of three components:

(1) the preparation by each Agency of an Inventory of Current and Planning Health Statistical Activities;

(2) the preparation by each Agency of an Agency Health Statistics Plan; and

(3) the synthesis of Agency submissions into a Departmental Plan.

The scope of the Plan encompases all general purposes and program-specific health data projects and systems of the Health Care Financing Administration (HCFA), the Public Health Service (PHS), the Office of Human Development Services (OHDS), and the Office of the Assistant Secetary for Planning and Evaluation (OASPE).

The terms "health statistics" or "health data activities" include several types of activities. In addition to national multipurpose surveys, censuses and inventories, virtually every one of the diverse health programs of the Department collects and uses quantitative information in program administration. The Plan also includes single time surveys and major statistical projects incident to health evaluation and research activities.

ORGANIZATION OF HEALTH STATISTICS SYSTEMS IN THE DEPARTMENT

Within the Department, the organization of and decision-making structure for health statistical activities, both for general purpose use as well as for program-specific purposes, is shared among the various organizational units of the Department. These include virtually every health program of the Public Health Service, the Health Care Financing Administration, the Office of Human Development Services and other agencies. The National Center for Health Statistics is the focal Federal agency for general purpose health statistics.

The following five subject matter categories comprise the framework into which most of the varied health data projects and systems carried out in the Department can be organized:

- Health Status -- describes measures of the nature and extent of disease, disability, discomfort, attitudes and knowledge concerning health, and of the perceived need for health care and health services of persons and populations. Data for measuring health status are acquired largely from general purpose sample surveys and census sources.

- Health Care Resources -- describes the health care personnel, institutions, agencies, and facilities including their services, equipment, and knowledge and skills. These data are obtained primarily from licensure, certification, and other records and periodic inventories.

- Use of Health Services -- describes the uses and users of preventive and curative health services and health resources and should measure both the volume of use or activity and the person who use the services. These data are obtained largely from general purpose surveys and from medical and claims records.

- Financial Aspects of Health -- includes measures of costs, prices, charges, and payments that reflect the financing from both private and public sources to create health care resources and pay for their use. The data are obtained from general purpose surveys, from progam-specific sources, and from flow-of-funds studies.

- Health Care Outcomes -- describe the end results of the health services provided. These are necessary measures to assess the "output" of the health care system and to complete the logical sequence in the conceptual model. Gross measures of health outcomes are derived from program specific sources as well as from general purpose surveys.

DESCRIPTION OF EXISTING DEPARTMENTAL HEALTH DATA ACTIVITIES

HEALTH CARE FINANCING ADMINISTRATION

As the agency responsible for the Federal government's two major health care financing programs -- Medicare and Medicaid -- the Health Care Financing Administration (HCFA) maintains large data files describing Federal health care expenditures, health care providers, and HCFA program beneficiaries.

Medicare program statistics are maintained centrally on a person level basis. Linkages are made across beneficiary, claims and provider information. Medicaid program statistics at the Federal level are aggregate and do not allow for person based linkages and analyses. The majority of these data are produced as a direct result of bill processing and related support systems established to reimburse providers of health care services under Medicare and Medicaid.

The Medicare program reimbursement systems, for the most part, are operated by a nationwide network of contractors (fiscal intermediaries and carriers). Under the Medicaid program these types of systems are operated by State Medicaid agencies or their designated fiscal agents, under the general oversight and direction of the Health Care Financing Adminisration.

HCFA's health data can be divided into four general categories:

- data related to provider reimbursement systems, including information on the nature and costs of health care services received by HCFA program beneficiaries;
- data related to HCFA's quality assurance programs, which are required for the monitoring of quality characteristics of health care providers and which includes data to support peer review under the Professional Standards Review Program in the form of provider profiles and "norms" of health care;
- data related to program and project evaluation, including empirical evaluation studies of the impact of major programs and demonstration projects on an ongoing basis; and
- data related to research and initiatives in the area of cost containment and health care reimbursement reform.

DESCRIPTION OF EXISTING DEPARTMENTAL HEALTH DATA ACTIVITIES

PUBLIC HEALTH SERVICE

The Public Health Service is the principal health agency of the Federal Government. Its mission, in its broadest and simplest terms, is to protect and advance the health of the American people. Health data activities of the Public Health Service, both general purpose and program-specific, support this mission. Because of their diversity, major organizational units of the Public Helath Service are outlined separately and include the following:

- Alcohol, Drug Abuse and Mental Health Administration
- Centers for Disease Control
- Food and Drug Administration
- Health Resources Administration
- Health Services Administration
- National Institutes of Health
- Office of the Assistant Secretary for Health
    - National Center for Health Statistics
    - National Center for Health Services Research
    - National Center for Health Care Technology

PUBLIC HEALTH SERVICE

Alcohol, Drug Abuse and Mental Health Administration

The Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) has responsibility for national research, training and services in the areas of alcoholism, drug abuse and mental illness. Its three component agencies:

- the National Institute of Mental Health (NIMH);
- the National Institute on Alcohol Abuse and Alcoholism (NIAAA);
- the National Institute on Drug Abuse (NIDA).

The three agencies each engage in a number of significant statistical activities directed at:

- identifying the location and characteristics of facilities, programs and personnel providing services to their target population;
- counting the numbers and characteristics of persons served by their program funds;
- determining charges and sources of payment for services; and
- assessing the effectiveness of services provided.

The statistical activities of each Institute are specifically tailored to serve its particular program needs. An overall ADAMHA Data Coordinating Committee is continuing to work toward the development of common definitions and categories for patient, facility, and staff variables.

PUBLIC HEALTH SERVICE

Centers for Disease Control

The Centers for Disease Control (CDC) are the Federal Government's focal point for the prevention and control of preventable disease, laboratory improvement, health education and occupational safety and health. The mission of the Centers is to lead public health efforts to prevent unnecessary disease, disability, and premature death.

CDC pursues this mission through activities to:

- prevent and control chronic and infectious disease;
- prevent disease, disability and death associated with environmental and occupational hazards;
- promote public health education on the leading causes of disease, disability and death;
- encourage State and local capacity building for expanded public health roles in problem areas;
- to provide technical assistance and support to State and local health agencies and others engaged in prevention activities

The Centers for Disease Control also provide support to local, State, national, and international prevention efforts in the basic disciplines of epidemiology, laboratory sciences, and training.

The CDC health information systems include the following general categories:

- Routine weekly and annual reporting of morbidity data collected through State agencies (e.g. infectious disease, lead-based paint poisoning);
- Detailed epidemiologic data or information on individual cases collected through State health departments;
- Surveillance of certain selected health concerns such as congenital defects, hospital-acquired infections, surgical sterilizations, and immunization levels.

PUBLIC HEALTH SERVICE

Food and Drug Administration

The Food and Drug Administration (FDA) is a regulatory agency whose mission is consumer protection in certain areas of health. FDA plays a significant role in influencing the Nation's health status and in assuring the effectiveness of the Nation's health care delivery system by ensuring that:

- food is safe and wholesome;
- drugs, biological products, therapeutic devices, and diagnostic products are safe and effective;
- cosmetics are safe;
- the use of radiological products does not result in unnecessary exposure to radiation; and
- that all of these products are truthfully labeled.

FDA supports several major health data collection projects. In addition, FDA engages in special studies dealing with nutrition education and knowledge, food additives usage, perceptions concerning product labelling and patient-package inserts, adverse reactions to drugs and cosmetics, and prescription drug advertising.

PUBLIC HEALTH SERVICE

Health Resources Administration

The Health Resources Administration (HRA) is responsible for identifying health care resource problems and maintaining or srengthening the distribution, supply, use, quality and cost-effectiveness of these resources in order to improve the health care systems and the health status of individual members of the population.

In order to carry out this mission, the Health Resources Administration requires extensive data on the health status of the population, the accessibility to and use of health care services, and measures of the Nation's health planning and resource development capacities, especially its manpower production capacity.

PUBLIC HEALTH SERVICE

Health Services Administration

The Health Services Administration (HSA) has responsibility for those programs of the Public Health Service that deal with direct service delivery to statutory beneficiaries, building the primary care capacity for medically underserved populations, and for assuring quality in Federally financed health care services.

Direct health care services are provided in Public Health Service facilities and with PHS employees, to American Indians and Alaska natives and to merchant seamen and other designated beneficiaries.

The Bureau of Medical Services is responsible for health care services provided in PHS hospitals. It operates several data systems to provide planning and management information both for PHS hospitals and outpatient clinics.

The Indian Health Service provides comprehensive health services to American Indians and Alaskan Natives. Nine data collection systems managed by IHS supply information on services provided both by IHS hospitals, clinics, clinical laboratories, and by community, social, mental health workers for planning, management and evaluation purposes.

The Bureau of Community Health Services oversees a number of categorical programs that provide medical services for underserved populations. Through a management data system called the Bureau of Common Reporting Requirements it collects uniform program data from all health services delivery poejects which are funded by BCHS. Data is collected on patient characteristics, service utilization, staffing, and costs.

PUBLIC HEALTH SERVICE

National Institutes of Health

The National Institutes of Health (NIH) is the lead Federal agency for biomedical research concerning the cause, prevention, diagnosis, and treatment of disease. The 11 research institutes of the NIH both conduct research in their own facilities and support research projects in universities, hospitals, and other non-Federal organizations.

The management of such an enterprise involves decision making requiring a wide variety of data. One type of data focuses on the incidence, prevalence, and related morbidity of specific diseases. The National Institutes of Health use these data for purposes of establishing research priorities for the study of diseases, to apportion research resources, and to determine population subgroups that may be a highest risk levels.

In addition, NIH maintains data collection projects which are epidemiological studies designed to trace the patterns of disease, test specific hypotheses regarding the conditions and factors associated with significant disease rates, to identify risk factors in the population, and to determine the effectiveness of various diagnostic and treatment modalities.

PUBLIC HEALTH SERVICE

Office of the Assistant Secretary for Health

The Office of Health Research, Statistics and Technology (OHRST) is the principal office within the Office of Assistant Secretary for Health concerned with health statistics. OHRST includes the National Center for Health Care Technology, the National Center for Health Services Research, and the National Center for Health Statistics.

National Center for Health Statistics (NCHS) --

The mission of NCHS is to:

- collect, analyze, and disseminate national health statistics;
- administer the Cooperative Health Statistics System;
- conduct research in survey and statistical methodology;
- coordinate the effort of Departmental agencies in health statistics;
- cooperate in international health statistics activities;
- serve as a national focal point for health data.

As the general purpose statistical agency of the Federal Government, NCHS provides the public with a range of data needed to assess current health status and services and to identify emerging needs. Its findings are disseminated primarily through NCHS publications, public-use data tapes and articles in health journals.

The data systems of the National Center for Health Statistics include:

- General Population Surveys -- in the annual Health Interview Survey, NCHS collects information on illness, injuries, and disability in the population and on the costs and use of health care. The Health and Nutrition Examination Survey (HANES) is the source of data from special physical examinations on the prevalence of chronic diseases and related health care needs, nutritional status, and other health measurements.
- Vital Statistics -- from information on the records of births, deaths, marriages, and divorces maintained by States, NCHS produces the Nation's official vital statistics. In addition, data is collected on fertility, family planning, and infant and maternal health through the National Survey of Family Growth.

- Ad Hoc Surveys -- periodic surveys based on samples of vital records to obtain health data not available from those records.
- Cooperative Health Statistics System -- a shared system operating to meet data needs of public and private agencies at National, State, and local levels.
- Health Resources Surveys -- periodic inventories of inpatient health care facilities, family planning clinics, and selectd health occupations to obtain data on the number, location, and characteristics of these resources.

National Center for Health Services Research (NCHSR) --

The mission of the NCHSR is to:

- undertake and support research, demonstrations, and evaluations on problems in the organization, delivery, and financing of health care services;
- serve as the focal point for coordination of health services research within the Public Health Service;
- disseminate the findings of health services research to policy and decisionmakers in the public and private sectors.

NCHSR conducts and supports research, demonstrations, and evaluations concerning the delivery of health services, including:

- the design, utilization, organization, and cost of facilities and equipment;
- the uses of computer science in health services delivery and medical information systems;
- a program to provide effective and timely dissemination of the findings of research by means of publications, conferences, and workshops.

National Center for Health Care Technology (NCHCT) --

The mission of the NCHCT is to conduct and support activities in health care technology assessment and to coordinate these efforts throughout the Department.

Technology assessment includes studies of the safety, efficacy, effectiveness, cost-effectiveness, and the social and ethical implications of technologies. This research and evaluation serves to promote the appropriate use of diagnostic techniques, medical and surgical procedures, and other health care technologies.

In carrying out these assessment activities, NCHCT:

- supports and conducts the development and testing of methodologies for assessing the safety, efficacy, and effectiveness of particular health care technologies and their social, economic, and ethical impacts;
- coordinates the technology assessment activities of agencies within the Department;
- commissions syntheses of existing knowledge, that is, so-called "state-of-the-art" papers; and
- disseminates information derived from its assessment activities to the practicing and research communities, Federal agencies, third-party payors, and the public.

REPORT
# of the
INTERAGENCY TASK FORCE
on
THE HEALTH EFFECTS
OF IONIZING RADIATION

Printed and distributed by the
Office of the Secretary,
U.S. Department of Health, Education, and Welfare
Washington, D. C.

June 1979

IV. PERSONAL PRIVACY AND RESEARCHERS' ACCESS TO RECORDS

To conduct epidemiologic research, scientists must have access to records containing personal, individually identifiable information. With respect to a population exposed to radiation, researchers must gather data on the personal characteristics and living habits of the individuals comprising the population, on the nature and extent of the exposure under investigation, on the health outcomes of those exposed and, if possible, on additional exposures to other sources of radiation or to other toxic agents. Since health effects may occur many years after the exposure, researchers must be able to trace individuals exposed in the past to discover their present situation. Often, researchers must also find a group of individuals with comparable characteristics that has not been exposed to the source of radiation being studied.

Researchers glean these data from numerous records held by federal agencies, state and local agencies, and private recordkeepers. Compilation is a lengthy, painstaking and expensive process. Among the difficulties encountered by researchers seeking access to records in recent years are legal barriers erected by legislatures, courts, and agencies concerned about invasions of personal privacy. Generally, the focus of concern has not been the use of personal information in health research, but rather the possible misuse of such information by public agencies or private companies in decisions affecting the individual. 44/ Nonetheless, laws have been written broadly enough to bar or to delay researchers' access. Further, there is legitimate concern about researchers' redisclosure of individually identifiable information to non-researchers.

Because of the need for scientifically sound, efficient and timely epidemiologic research into the health effects of radiation, the Records and Privacy Work Group was formed to examine the extent to which legal barriers presently impede access to necessary records and to recommend changes in the law and administrative policies that would accommodate both the public interest in effective health research and the privacy interests of individuals.

44/ See Personal Privacy in an Information Society: The Report of the Privacy Protection Study Commission, pp. 570-74.

A. Legal Restrictions on Researchers' Access to Records

Many of the most useful records for radiation research are maintained by federal agencies. These include: Internal Revenue Service (IRS) records, which are primarily important for locating individuals and establishing death; Social Security Administration (SSA) records, which are useful for locating individuals, establishing death, or showing health status, and identifying the nature of employment; Office of Personnel Management records, which help to locate and to establish death of federal employees; Veterans Administration (VA) records, which contain information on location, employment, and health status or death of veterans; and Department of Defense (DoD) records, which provide information on exposures, health status and location of individuals exposed to radiation in the military.

Federal contractors, including the companies that operate DoE facilities, also maintain records containing information about exposures and health status of present and past employees. Regulated employers may maintain similar records. Finally, states have numerous vital records on births, deaths, and similar events which are very helpful to researchers. State health departments or universities often maintain cancer registries with pertinent personal and employment information about individuals with cancer.

Various laws restrict health researchers' access to these records and affect the privacy rights of the record subjects. The Privacy Act limits disclosure of certain individually identifiable records held by federal agencies and federal contractors. Four exceptions to the act permit most disclosures sought by agency or private researchers. The "routine use" exception, the most commonly used provision, permits disclosure of certain records for a use "compatible" with the purpose for which the record was collected and is usually interpreted broadly. Establishment of a "routine use" requires publication in the Federal Register and an opportunity for public comment. If researchers do not anticipate their need for certain records, or if the agency holding the records proves uncooperative, access may be delayed. A more serious difficulty arises from the fact that since each agency establishes its own "routine uses," standards for disclosure for research purposes vary among the agencies and some important records cannot be obtained. From the point of view of the record subject, the Privacy Act is not fully satisfactory because there are no restrictions on later redisclosure or misuse of record information by researchers.

Other federal statutes present more serious impediments to researchers than the Privacy Act. The Tax Reform Act of 1976 in effect bars use in epidemiological research (except for research performed by NIOSH) of any tax return information held by the IRS or by SSA. The VA's confidentiality statute prohibits it from disclosing names and addresses of veterans or their dependents to researchers not employed by federal or certain state health agencies, thus preventing establishment of linkages necessary for epidemiological research.

Private employers who are federal contractors are subject to the Privacy Act under some conditions, and their records are disclosable to researchers employed by the contracting agency or, under routine uses, to other researchers. However, some contractor records are not covered and, as a practical matter, many contractor records are either unavailable or in poor condition. Employers in industries regulated by the NRC are required to maintain certain records, but these are not intended for use in epidemiological research and are not complete. The situation is similar with respect to employers regulated by OSHA, although OSHA now considers research needs in setting record-keeping requirements. Although many private employers maintain useful records on their own initiative, they rarely choose to open these records to federal agencies and researchers' legal rights of access to these records are unclear.

Finally, although epidemiologists generally have full access to state vital records, these sources are dispersed, cumbersome to use, and, in the case of death certificates, may not always be accurate in describing the cause of death. Disease registries provide substantial information, but are often incomplete and may be subject to some restrictions on both disclosure and redisclosure.

B. Recommendations

Although some statutes do create difficulties, sufficient information does exist, generally in vital records, to permit researchers to perform their work. However, research could be made significantly easier, more accurate and less expensive, without endangerment of privacy rights, through modification of administrative policies and some statutes. The Records and Privacy

Work Group recommended the following changes, which have been endorsed by the Task Force.

1. Federal Records

a. The Privacy Act

- OMB should issue specific guidelines, after consultation with interested agencies, clarifying the extent to which, and the circumstances under which, researchers may lawfully have access to federal records under the Privacy Act. OMB should also continue to be available to mediate disputes as to the interpretation of the Privacy Act in specific cases.
- The Administration's proposed legislation should be passed. This bill clarifies the circumstances under which health researchers may have access to federal records, and delineates specific safeguards against uses of federal research records for purposes other than research.

The purpose of these recommendations is to ensure that a consistent federal policy on health researchers' access to federal records is adopted. OMB guidelines would be helpful whether or not new legislation is enacted. Absent legislation, guidelines could clarify agencies' application of the "routine use" exception to the Privacy Act in particular.

Legislation has recently been proposed by the Administration, giving researchers a clear right to use most federal records while also providing safeguards to individuals by limiting use or redisclosure of records for non-research purposes. This legislation applies to all federally sponsored research, is modeled on the recommendations of the Privacy Protection Study Commission, and accords with the recommendations made by the Records and Privacy Work Group. 45/ Legislative action is favored over broad interpretation of the routine use exception to accommodate worthwhile research, a practice which may create unfortunate precedents in non-research contexts.

45/ See Records and Privacy Work Group Report, pp. 12-16.

b. Tax Reform Act

Section 6103(a) of the Internal Revenue Code should be amended to authorize IRS and SSA to disclose return information for purposes of health research under circumstances and conditions which are consistent with the recommendations above for amendment of the Privacy Act.

Because of the loss of time, the expense and the risk of failure that result when researchers must rely exclusively on decentralized state, local, and private resources, the Work Group concluded that researchers should be given access to IRS and SSA records. Because of the need to protect individual record subjects, the Work Group concluded that access should be for the limited purpose of health research only, with appropriate restrictions on use and redisclosure of information. 46/

c. VA Confidentiality Statute

Legislation should be proposed to amend 38 U.S.C. 3301 to authorize the VA to disclose personal information, including the names and addresses of VA claimants, for health research purposes under circumstances and conditions which are consistent with the recommendations above for amendment of the Privacy Act.

Draft legislation to implement this recommendation is now being circulated to federal agencies by the Office of Management and Budget.

d. SSA Disclosure Regulations

In conducting their policy review of SSA disclosure regulations, the SSA Commissioner and the Secretary of HEW should pay special attention to the need of health researchers

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46/ One commentator suggested that the law be amended to permit researchers to obtain a release from research subjects, authorizing the researcher to trace them in the future through IRS records. Pub. Comm. doc. 7.

for SSA records. The HEW/SSA review should consider whether disclosures for health research outside of HEW would be "compatible" with the purpose for which SSA records are collected and maintained.

Regulations governing disclosure of SSA records, which have to date been very restrictive, are presently under review. SSA should attempt to accommodate health researchers in those regulations and, in particular, should focus on the question whether a routine use for disclosures to health researchers outside of HEW could be established.

2. Medical Records

Legislation proposed by the Administration should be passed. Under the bill, the disclosure of medical records maintained by health care institutions using federal funds would be prohibited without the patient's consent except in specified circumstances. One such circumstance should be for health research under the same circumstances and conditions recommended above for amendment of the Privacy Act.

This recommendation accords with the provisions of the Administration's medical records privacy bill, which was recently proposed to Congress. The legislation is modeled on the recommendations of the Privacy Protection Study Commission.

3. Vital Records

a. HEW should study the feasibility, in terms of cost, likely productivity, and the availability of necessary data, of making the National Death Index retroactive. The study should be undertaken reasonably soon after the Index is operational, and should consider the appropriate retroactive period, if any.

Researchers now rely primarily on state and local death certificates to ascertain mortality and cause of death. Establishment of the National Death Index by the National Center for Health Statistics (NCHS) in 1980 should relieve the time and expense of that investigation. However, the index as presently planned will include only deaths after 1979. If it is feasible to collect accurate information on earlier deaths, the index could be even more useful.

b. HEW should encourage the adoption of NCHS' model vital statistics statute and implementing regulations in order to facilitate health research disclosures.

NCHS' model vital records statute authorizes health research with appropriate safeguards. Adoption by all jurisdictions would obviate existing restrictions in a number of states.

4. Private Employer Records

The Director of NIOSH and the Secretary of HEW should review current HEW regulations to determine whether there is a need for further regulation to assure that records disclosed to NIOSH under the Occupational Safety and Health Act are protected from redisclosure for any purpose that might harm the record subject.

NIOSH's right of access to private employer records has recently been challenged in litigation, during which a claim has been made that employees' privacy rights are threatened by disclosure of employers' records without employees' consent. Steps should be taken to reassure all parties that the records obtained by NIOSH will not be used for any purpose that might harm the employee. Use for epidemiological research and for enforcement of workplace standards by OSHA would be permitted.

Effective implementation of the recommendations outlined above would facilitate and reduce the cost of epidemiologic research, while providing individuals who are the subject of research with safeguards against misuse of information about them.

6/2/81

INSTITUTE OF MEDICINE
NATIONAL ACADEMY OF SCIENCES
2101 CONSTITUTION AVENUE WASHINGTON, D.C. 20418

FREDERICK C. ROBBINS, M.D.
PRESIDENT

May 27, 1981

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Chairman
Subcommittee on Natural
Resources, Agriculture
Research and Environment
Committee on Science and Technology
U.S. House of Representatives
Washington, D.C. 20515

Doug Walgren
Chairman
Subcommittee on Science,
Research and Technology
Committee on Science and Technology
U.S. House of Representatives
Washington, D.C. 20515

Dear Mr. Chairmen:

On behalf of the Institute of Medicine committee charged with the conduct of a study, "Costs of Environment-Related Health Effects," I am pleased to submit a statement in response to your request. We hope that the statement can be included in the record of the hearings being conducted by your subcommittees on "A Coordinated Health Information System: Needs, Issues, and Planning."

I was privileged to be a member of the Institute committee that conducted this study which was chaired by Kenneth Arrow of Stanford University.

We trust that the attached statement responds to your request for information on the IOM study, and we thank you for the opportunity to submit a statement.

Sincerely yours,

Enclosure

Statement of

Frederick C. Robbins
President
Institute of Medicine
National Academy of Sciences

for the

Subcommittee on Science, Research and Technology
Committee on Science and Technology
House of Representatives

May 27, 1981

Problems of coordinating health information among the many sources of relevant data have long concerned the Institute of Medicine. I am therefore particularly pleased that this committee considers the issue important enough to address in hearings, and the Institute of Medicine is pleased to submit this statement for the record in response to your request. I will describe some of the relevant findings of the most recent activity the IOM undertook that dealt specifically with the need for improved collection, analysis, and coordination of health data.

The Institute of Medicine recently completed a report on Costs of Environment-related Health Effects: A Plan for Continuing Study. The project was undertaken in response to Section 7 of Public Law 95-623, in which Congress called for an ongoing study that would, among other requirements, address "present and projected future health costs of pollution and other environmental conditions resulting from human activity". The ongoing study would provide information on sources of environmental hazards, health effects attributable to those sources, and costs of these health effects.

More significantly for purposes of the committee's inquiry, the law calls also for biennial reports that identify deficiencies in the available data and recommend corrective actions. Thus, in passing this law Congress recognized that great improvements were needed in data to determine health costs associated with the environment. Because of the broad scope of Section 7, the Institute of Medicine undertook a planning study, so that the ongoing study could proceed most effectively.

The study committee that the Institute of Medicine formed to develop the plan defined the environment broadly to include all non-genetic factors that affect human health, but focused primarily on those aspects of the physical and chemical environment to which people are involuntarily exposed. However, genetic differences in suceptibilities to environmental factors were addressed. Attachment A lists the committee roster. To put the following discussion of data needs in perspective, the full summary of the report is included as Attachment B.

In carrying out its study, the IOM committee worked closely with the National Center for Health Statistics. Section 8 of Public Law 95-623 specified activities that NCHS was to carry out related to improving coordination of environmental statistical information within the government. In a report entitled Environmental Health: A Plan for Collecting and Coordinating Statistical and Epidemiologic Data, published in 1980, NCHS identified 64 information data systems in 18 federal agencies that gather information of use of environmental health epidemiologists. NCHS notes that few of these systems attempt to link environment and health data. Two other NCHS activities stemming from P. L. 95-623 involved preparation of the two reports entitled Guidelines for Statistics and Information on Effects of the Environment on Health and Environmental Health: A Study of the Issues in Locating, Assessing, and Treating Individuals Exposed to Hazardous Substances.

One of the major goals of the Institute of Medicine planning study was to describe the basic information requirements necessary for the ongoing study and biennial reports called for in the law. The committee developed Figure 1 to summarize the kinds of information needed to obtain the required cost estimates, and quickly learned that many of the required data are lacking or are not available in a useful form. For example, data related to air or water quality are not collected in a way that is useful for determining associated health effects; exposure data are particularly difficult to obtain. Similarly, data on health care are often difficult to relate to health costs.

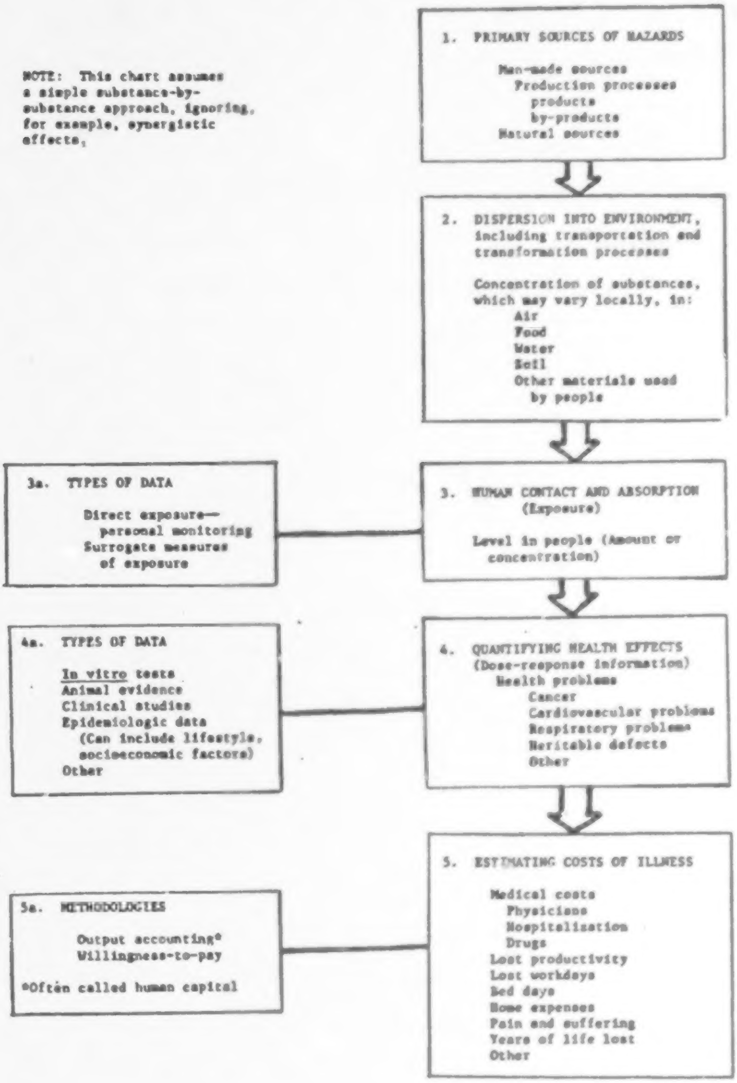
Thus, much of the committee's attention and recommendations focused on the need to improve the available data, recognizing that any efforts must be long-term. Nonetheless, the rewards would be substantial, in that such efforts could result in more efficient use of limited resources, and would be helpful in monitoring the effects of actions taken to improve health or to decrease health costs.

Among the broad goals that the committee identified for the ongoing study were the need to integrate available data and coordinate statistical policy. Other recommendations addressed aspects of using existing data systems more effectively, as well as setting up new data systems and data collection activities in a more coordinated fashion that has generally been true in the past. The need for long-term epidemiologic studies was emphasized.

The committee recommended that "whenever possible, existing data and data systems be used to the fullest extent" since analysis of existing data, if adequate for the purpose, is generally less expensive than collection of new data. The committee added that existing data and data systems and surveys should be expanded, where feasible, to aid discovery of associations between exposure and health outcome. As examples, the National Occupational Hazard Survey conducted by the National Institute for Occupational Safety and Health, or the National Health Survey, conducted by by the National Center for Health Statistics, could be expanded to provide additional information.

Emphasis was placed on the need to integrate and link the existing data systems scattered among various agencies. Thus, the committee notes "data integration among current large data collection activities should be carried out so that health outcome data can be related to environmental exposure data. However, all such efforts must be consistent with the need to protect confidential information and individual privacy." The report continues by noting that many agencies collect data that could be shared by other agencies

FIGURE 1. CHART OF INFORMATION NEEDED TO ESTIMATE THE COSTS OF ENVIRONMENT-RELATED HEALTH EFFECTS AS MANDATED BY PUBLIC LAW 95-623


NOTE: This chart assumes a simple substance-by-substance approach, ignoring, for example, synergistic effects.

1. PRIMARY SOURCES OF HAZARDS
Man-made sources
Production processes
products
by-products
Natural sources
2. DISPERSION INTO ENVIRONMENT, including transportation and transformation processes
Concentration of substances, which may vary locally, in:
Air
Food
Water
Soil
Other materials used by people
3a. TYPES OF DATA
Direct exposure—personal monitoring
Surrogate measures of exposure
3. HUMAN CONTACT AND ABSORPTION (Exposure)
Level in people (Amount or concentration)
4a. TYPES OF DATA
In vitro tests
Animal evidence
Clinical studies
Epidemiologic data (Can include lifestyle, socioeconomic factors)
Other
4. QUANTIFYING HEALTH EFFECTS (Dose-response information)
Health problems
Cancer
Cardiovascular problems
Respiratory problems
Heritable defects
Other
5a. METHODOLOGIES
Output accounting*
Willingness-to-pay
*Often called human capital
5. ESTIMATING COSTS OF ILLNESS
Medical costs
Physicians
Hospitalization
Drugs
Lost productivity
Lost workdays
Bed days
Home expenses
Pain and suffering
Years of life lost
Other

without introducing problems of confidentiality, but that these data often are not compatible. The committee recommends that data collection be made more standardized so that data sets are compatible.

Among its other recommendations, the committee gave high priority towards continuing efforts to coordinate statistical efforts at all government levels. Questions concern data compatibility, confidentiality, purposes of the various agencies that collect data, and funding arrangements for collection of data that would be used by more than one agency. Various groups, both within and outside the federal government, should explore the administrative questions that hinder coordination of statistical policies and sharing of data, and should seek feasible solutions.

While recognizing the desirability of coordinating health and environment and cost information, the committee also acknowledged the myriad difficulties any such effort involves. At the federal level, data are collected by various agencies to serve the functions of that agency. This collection of programs is not integrated, and many problems would accompany attempts to change these systems. Chief among these are issues of confidentiality and privacy. Not only are there rules against agencies allowing confidential information out of the government, but also strict limits against sharing many kinds of confidential information among agencies. Current federal law also inhibits data sharing with the states.

But a coordinated health information system is not limited to data from public groups. Private organizations, such as industry, labor unions, academic researchers, consumer groups, insurance agencies, health care providers, and others, also have health data which are part of the entire picture. These need also to be integrated with federal systems, and their cooperation sought in any effort for coordinating health data systems.

In setting up new data systems, experts in relevant fields should work together to make the resulting data useful in deriving relationships among environment, health effects, and costs. Health professionals, environmental professionals, economists, and others should plan together. For example, if a system to monitor health effects of a particular occupational exposure is set up, data collected should be sufficiently detailed to permit reliable cost estimates. Use of broad-based groups to plan for data collection is also likely to increase the chance that various systems will be compatible.

The committee recommends that longitudinal studies be undertaken, and that considerable attention needs to be addressed to improving morbidity, as opposed to mortality, data. Acute exposure incidents, if monitored systematically, can provide coordinated information on exposure, outcome, and costs.

The workplace provides another source of information that would be particularly useful for obtaining information in a coordinated way so as to discover causal relationships. Programs for collecting occupational exposure data should be systematized to permit linkage with data on disease, disability, and death, and with other kinds of health outcome data. The committee recommends that special efforts should be made to monitor people working under new conditions to detect early problems. Lifetime work records should be available for an individual so that health and exposure data could be related. It would also be desirable to link NOHS and Social Security data to relate health outcome and occupation. Uniform recording of occupation and industry on death certificates should be encouraged.

Health cost data also were considered by the committee, which noted that better use could be made of Medicare Part B records, the National Medical Care Utilization and Expenditure Survey, the National Medical Care Expenditure Survey, and third-party payers, especially the data of the Federal Employees'

Health Benefits Programs. Although these all have limitations, they are potential sources of health cost and utilization data. In addition, profiles of medical care costs over time incurred by individuals with specified health problems should be obtained in a longitudinal study.

Data related to health information will not be easy to integrate, but the committee strongly concurs that the effort should be made as vigorously as possible and as soon as possible.

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Attachment A

INSTITUTE OF MEDICINE

PLANNING STUDY FOR AN ONGOING STUDY OF COSTS OF ENVIRONMENT-RELATED HEALTH EFFECTS

COMMITTEE ROSTER

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SUMMARY

This report presents a plan for a congressionally mandated study of costs of environment-related health effects. It includes a framework for an ongoing study that would improve the data and methodologies available to relate environmental hazards to health problems and the costs of these health problems. However, the committee that is presenting this plan and related findings also cautions that the broad scope of the congressional charge far exceeds what is feasible in our present state of knowledge and that a more systematic effort that evolves over time is needed to derive consistent information on costs of environment-related health effects.

Ways that environmental factors affect human health and well-being have attracted growing attention in recent years, with much illness and disease now believed to be associated with environmental factors. The environment in this context includes all extrinsic factors that affect human health. Modification of environmental conditions should provide a promising opportunity for reducing illness and disease and their associated costs. There also has been increasing concern about costs of illness--medical costs in 1979 were $212 billion, or 9 percent of the Gross National Product. In addition, questions are being raised about the effects on the economy of the almost two dozen environment-related laws enacted in the 1970s. While estimates of costs associated with attempts to improve the environment abound, data on the health benefits attributable to these improvements are scarce.

Recognizing a need for more adequate information, Congress enacted Public Law 95-623, the Health Services Research, Health Statistics, and Health Care Technology Act of 1978. This report responds to Section 7 of the law, which calls for an "ongoing study of the present and projected future health costs of pollution and other environmental conditions resulting from human activity," and the reduction in health costs that would result from changes in these conditions. Thus, the law asks for estimates of the health benefits of an improved environment. It calls also for biennial reports that include recommendations on matters related to the ongoing study.

Because of the law's broad scope, the planning committee considered which aspects of the environment should be studied first. In its broadest context, the environment includes all extrinsic, that is, non-genetic factors that may influence health, including agents in the natural environment, such as sunlight, and factors directly attributable to human activity, such as exposure to synthetic chemicals. Many factors in the environment are beneficial in moderate amounts, such as fluorides in drinking water, but harmful in large amounts. Environmental conditions include activities often classified as "lifestyle" or "voluntary," such as habits of nutrition, alcohol consumption, and smoking, and conditions usually considered "involuntary," such as exposures to noise, chemicals, air pollutants, and radiation. Factors related to the social environment and socioeconomic status also are part of the human environment.

The committee recognizes that these many environmental factors interact with each other and with the individual to influence health status. Nonetheless, after extensive discussion of the law's apparent intent, the committee recommends that the ongoing study focus initially on adverse health effects and their costs resulting from involuntary exposures to physical and chemical agents derived from human activity, taking into account other factors when they modify the effects of these physical or chemical agents. For example, studies of respiratory illness among miners should include smoking history. Whenever possible, data related to these other factors should be collected and made available for later analysis.

Diseases and illnesses of concern include those mentioned in the law, such as heart disease, respiratory illness, and birth defects, but are not limited to these. Environmental factors can adversely affect many parts of the body, such as the skin, the nervous system, the immune system, and the reproductive system.

Conduct of the ongoing study requires information related to sources of environmental hazards, human exposure to these hazards, resulting health effects, and, finally, costs attributable to these health effects. The Institute of Medicine undertook this planning study to facilitate the ongoing study's proceeding in an orderly and useful way.

The planning study goals, as related to the organization of this report, were to:

- describe the basic information requirements necessary for the ongoing study and for the biennial reports [Chapters 2,3,4]
- provide a framework for the ongoing study and an assessment of the feasibility of meeting the various requirements of the law [Chapters 3,4,6]

- recommend administrative arrangements for carrying out the ongoing study [Chapters 5,6]

- recommend steps to maximize the usefulness of the biennial reports [Chapters 5,6].

The committee recognizes the desirability of developing the kind of information and analyses requested in Public Law 95-623. It emphasizes that there are major deficiencies in data bases, methodologies, administrative procedures, and most important, theoretical knowledge for relating environmental hazards to health problems and their associated costs. These have precluded earlier straightforward assembly of the information. It is the committee's view that it is useful to attempt to develop the estimates requested in P.L. 95-623--even though much of the information cannot be provided in the near future--because improvements in data and methodologies can advance basic knowledge and lead to more informed decisions.

In the early stages of the ongoing study, it will become more apparent to what extent the goals of the ongoing study can be met. There will be substantial uncertainties in any estimates of health effects and costs the ongoing study develops, but the committee concluded that these uncertainties can be reduced and that more informed decision making will thereby result. Recognition of the degree of uncertainty can itself guide decision making and the collection of new information.

The committee has not proposed a step-by-step plan for the ongoing study, but rather a series of phased activities, including case studies, methodological research, and evaluative efforts to develop the required data bases and strategies for analyzing them. The ongoing study will differ from many related studies because it will emphasize the entire spectrum of information and techniques needed to get and analyze the data. The framework of required information that provides the basis for the committee's findings and recommendations is presented in Chapter 1.

Approach for the Ongoing Study

The committee identified several broad goals for the ongoing study:

- Integrating available data

The ongoing study should help generate, coordinate, and integrate environmental and health data for use in identifying relationships among health problems and their environmental causes and to enable evaluation of the consequences in terms of health costs. Although this planning study primarily emphasizes epidemiologic data, that does not reduce the importance of research on animals and other organisms to discover risk factors in advance of human exposure and to extend the information obtained from human studies.

- Coordinating statistical policy

The study should encourage various groups, especially in the federal government, to explore the administrative and policy questions that hinder coordination of statistical information. Data integration and linkage among current large data collection activities should be encouraged, consistent with the protection of confidential information and individual privacy.

- Developing health cost estimates

The ongoing study should lead to improved data and methods for evaluating and expressing health costs in monetary terms, as well as in terms other than dollars, such as number of days ill.

- Encouraging research

The ongoing study should highlight areas needing further methodological development and research, including basic biological research.

- Assuring continuity, funding, and flexibility

Because a short-term effort will not be particularly worthwhile towards achieving the goals of the ongoing study, provision for a long-term effort, including adequate funding, is required. Costs of carrying out the ongoing study will depend greatly on the extent to which the recommendations in this report are carried out. After reviewing available information in the early phase of the ongoing study, it should be possible to estimate to some extent costs of working towards filling the most pressing gaps in data and analyses, using criteria listed below for setting priorities. In some cases, it might be deemed not worthwhile to pursue certain activities because the costs of obtaining needed data may be great and the possible benefits relatively small or exceedingly uncertain. Costs associated with the ongoing study will need to be reassessed periodically in response to new conditions and information.

The Early Phase of the Ongoing Study

The early phase of the ongoing study should have the following four related and intertwined activities, which may continue in modified form throughout the study.

- Reviewing what is known

Information will be identified and assessed on the sources and amounts of pollutants, levels of human exposure to these environmental hazards, the health effects resulting from such exposures, and costs of the diseases and health effects of such pollutants. On the basis of this information, priorities for further studies of various environmental agents and health problems can be set according to the following criteria:

  - the magnitude of their known, suspected, or potential health impacts, taking into account the amount of the hazardous material in the environment

  - the reliability of existing knowledge about them and the potential usefulness of additional information in minimizing harmful effects

  - the public perception of their importance

  - the need to study them further for policy purposes.

- Assessing the importance and promise of available information

From the above activities, data needs will be identified, promising areas for research will be outlined, and additional recommendations will be made for assembling the required data.

- Developing illustrative case studies

Case studies will attempt to integrate the many kinds of information needed to meet the congressional request. The development of concrete cases should demonstrate the practical difficulties, complexities, and uncertainties encountered in providing the estimates Congress wants. It would be particularly important to extract from these case studies any generalizations that might apply to methodology and to economic, political, or ethical issues.

Two case studies should be undertaken at the outset. One would focus on a health problem and consider exposures as environmental determinants. The other would focus on a pollutant or source of pollution and consider all health consequences. Cost estimates would be attempted in both case studies. The approach should be to choose cases in which the etiologies are relatively well understood. These examples might serve:

Health problems--chronic respiratory disease, lung cancer, angiosarcoma, chronic disorders of the nervous system

Pollutants--asbestos, vinyl chloride, lead, nitrosoureas.

o Designing new methodologies

In addition to the studies indicated above, the ongoing study needs a program to develop new methodologies. Once systematic attempts are made to assess current information, it will become clear which areas require new methods to get quantitative results. The ongoing study, therefore, must explore the comparative merits of various data sources and methods for estimating health effects of the environment and their costs.

Some approaches entirely different from those customarily taken may merit development and appraisal. These could include new ways of assessing fractional contributions to illness and their costs other than on a substance-by-substance or disease-by-disease basis. On the biological side, animal and other laboratory models offer attractive alternatives to putting human beings at hazard and may save enormous effort and time in risk estimation for the human population. Also required is a consistent analytical methodology to model health outcomes on the basis of information from many different sources and of varying degrees of certainty.

The Biennial Reports

The biennial reports should contain data tables as well as the case studies and other descriptive material. Because methodological development is crucial, the committee suggests that periodically, as part of the ongoing study, a systematic review of the methodologies available or being developed to do the work of the ongoing study be collated, summarized, and published. Almost all estimates obtained as part of the ongoing study will have substantial uncertainty, that is, the actual values could be quite different from the estimate. The usefulness of the biennial reports will depend in part on how successfully the uncertainty is expressed.* As examples, public interest organizations, state and local officials, industry, labor, federal government officials, and researchers may use the data and reports for such specific purposes as setting policy, modifying work conditions, presenting a case in court, setting pollution emission standards, or planning a research project. In all these situations, estimates of the uncertainty of the available data and information on the methodological underpinning for estimates will be helpful.

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*Even if the uncertainty spans a range of one or more factors of 10, so that an estimate of 1000 might actually be 100 or 10,000 with some probability, that information may still be useful for making decisions. One of the goals of the ongoing study is to reduce these uncertainties.

The committee makes the following recommendations about expressing uncertainty:

> Estimates of uncertainty should be attached to each estimate of amount of pollution, health effect, or health cost.
>
> A description of the major sources of uncertainty should be provided.
>
> Whenever possible, the reporting system should employ numerical estimates, rather than imprecise terms such as "high," "medium," and "low."

Administrative Arrangements for the Ongoing Study

According to P.L. 95-623, the Department of Health and Human Services (DHHS) and the National Academy of Sciences (NAS) are jointly responsible for the ongoing study. The NAS is a private organization chartered to provide independent advice to the government. Several officials of the NAS believe it is inappropriate to undertake a study jointly with a government agency, because such an arrangement would compromise the NAS' historical role as an independent advisory body.

> This IOM planning committee recommends that the law be amended so that the NAS could serve in its customary advisory role.

It is believed desirable for the NAS to participate actively in the ongoing study on a continuing basis. Further details of the relationship would be arranged by officials of DHHS and NAS. Whatever relationship is arranged, the IOM planning committee recommends an administrative arrangement that fixes responsibility and authority for the ongoing study in one clearly defined body.

Within the constraints of the present law, the committee describes what it believes to be the best of several alternative arrangements it considered in attempting to delineate some areas of joint activity while preserving the NAS' role as an independent advisory body. Most of the particulars of this arrangement could apply whether NAS served in a preferred advisory capacity or in an arrangement involving joint responsibility. DHHS is assumed to be the lead government agency in the proposed arrangement, which entails formation of two committees, one organized by NAS and the second by DHHS, each with different responsibilities for carrying out specific tasks of the ongoing study. The NAS would establish a permanent committee with a rotating membership that included representation of the Institute of Medicine and other appropriate bodies within the NAS.

> The DHHS committee would have primary responsibility for operation of the ongoing study, for intergovernmental relationships involving the study, and for generating and assembling the data. The NAS committee would have lead responsibility for developing research goals, for much of the data analysis, and for overall evaluation of the program. The actual collection of the data would be the responsibility of individual agencies.

The two committees would have joint responsibility for other areas, such as developing priorities for each biennial report and the specifics of its preparation, and recommending areas for study and subjects for special monographs. The committees would review the reports and provide evaluations to the Secretary of HHS.

Chapter 5 presents other options for a lead federal agency and describes some of the difficulties inherent in coordinating an effort as extensive as the ongoing study. The various federal agencies, including those mentioned in the law, collect data in ways that respond to the needs of the particular agency, and appropriate incentives may be required to achieve the desired cooperation. However, voluntary cooperation should be sought by means that may include financial incentives and instructions, before further statutory means are undertaken. Many related efforts at coordination already exist; Appendix D lists about twenty interagency groups concerned with environmental health issues. This report emphasizes that whatever administrative arrangement is chosen should encourage mutually beneficial interactions with the many groups--both in and outside the federal government, including international organizations--that have an interest in the ongoing study.

Improving Information for the Ongoing Study

In addition to suggesting a framework and administrative arrangement for the ongoing study, this committee made recommendations to improve the data and methods needed to provide the estimates Congress requested. Recognizing that resources are scarce, the committee recommends that existing data systems be used to the fullest extent, and that they be modified or expanded where feasible to facilitate relating exposure to health outcome and associated health costs. If new data systems related to health, the environment, or health costs are set up, experts in fields relevant to the ongoing study should work together so that the resulting data systems are useful for the ongoing study.

Relating Exposure to Health Effects

There seldom is a simple relationship between environmental hazards and health effects. The contribution of a given environmental factor can vary, depending on the conditions under which it is encountered, the presence of other factors in the environment that may modify its effects, and the susceptibility of the population exposed. A given substance can lead to multiple health problems, and people are exposed to a variety of potentially hazardous substances in their surroundings. It is extremely difficult to determine causes of health problems that result from relatively low levels of exposure, especially if the resulting health problems occur after a long latent period and have no features specifically identifying them as environmentally caused. The need for new kinds of data is, therefore, great.

Appendix C illustrates the variety of health effects, ranging from mild discomfort to terminal illness, that have been associated with environmental factors. The committee emphasizes that

> Major efforts should be undertaken to improve our ability to relate environmental hazards to health outcome.

The greatest needs for improved data lie in the general areas of actual exposure of individuals and groups, and more complete reporting of morbidity, including partial disabilities, as well as mortality.

As described in Chapter 2, the exposure data needed to determine dose/response curves are rarely available. Exposure estimates are often based on calculations that use surrogate measures, such as ambient concentrations of materials in food, water, and air. Methods for more adequately assessing individual exposure should be explored.

Although exposure episodes resulting from industrial accidents or chemicals leaking from toxic dumps should be prevented by all practicable means, these inadvertent events can sometimes provide useful information about health effects of environmental exposure. Therefore,

> Incidents of acute exposure to environmental pollutants should be systematically used to determine associated exposure, health outcome, and cost.

Information on the number, timing, location, and nature of these events should be centralized within the federal government.

Several kinds of studies, discussed in Chapter 3, provide information about health effects of possible hazards. Surveillance programs among workers and other populations can monitor the effectiveness of efforts to prevent health problems from known hazards, and can also alert observers to new hazards.

Longitudinal studies, which follow individuals over an extended time, provide a broader range of information than can other epidemiologic study designs. As an example, the Framingham Heart Study, begun over 30 years ago, has elucidated some of the major risk factors in heart disease. For purposes of the ongoing study, the committee notes that longitudinal studies will be required to obtain dependable, useful, population-based information.

> Longitudinal studies and development of appropriate data bases should be undertaken, and the needed long-term commitments of funds and personnel assured.

The more powerful epidemiologic study designs also tend to be the more expensive. Appendix E gives some associated cost estimates.

In the workplace, the possibility of associating exposure with health outcomes is high, and occurrence of occupational disease often constitutes the first warning of a new environmental hazard. The exposed populations can be identified and followed and the exposures often can be quantified, at least to some extent. Furthermore, occupational populations may encounter new toxic substances sooner than does the general public, and in greater amounts.

Many of the previous recommendations for determining health effects apply particularly to the occupational environment. In general, any epidemiologic study should obtain information about occupation and industry where applicable. Additional specific recommendations for monitoring worker populations follow.

> Better information on occupational exposures should be sought. A National Occupational Hazards Survey should be conducted at regular intervals and the results disseminated widely.
>
> To highlight occupations with increased mortality, the feasibility of instituting a national decennial occupational mortality series, such as Great Britain produces, should be explored.
>
> A list of sentinel health events for occupational disease and illness should be developed to alert people to potentially preventable occupational health problems.

Problems of human reproduction received particular consideration from the committee. These problems include loss of libido, inability to conceive, having a miscarriage or stillbirth, or having a child with low birthweight, with physical or mental impairment, or one who develops cancer or other illness as a result of prenatal exposure. Environmental agents can affect the reproductive capacities of both males and females. Appropriate surveys and records are needed to monitor reproductive outcomes to associate adverse outcomes with possible environmental exposures, especially exposures that occur in the workplace.

Problems of individuals within the population with special susceptibility also were considered. These include individuals in certain age groups, for example, infants and the elderly, those who may have suffered previous exposures that led to heightened susceptibility, and those with particular genetic traits (See Appendix F). Identifying individuals of greater susceptibility to specific environmental factors can be important in developing occupational and environmental health policies, and in interpreting environment-related health statistics, but can also raise many difficult questions.

Estimating Costs

Cost estimates must be used with due recognition that they illuminate value judgments but do not replace them. They are not a substitute for the political and administrative processes of environmental decision making, but they are invaluable in informing them.

Estimation of costs will depend to a great extent on the data available to relate health problems to environmental hazards. However, even if these data were available, theoretical and practical problems would still make cost estimates difficult. Chapter 4 discusses some of the difficulties in estimating the costs enumerated in the law, using the two methods commonly employed to estimate costs of health effects in monetary terms--the output-accounting (or human-capital) approach and the willingness-to-pay approach. Output accounting measures direct costs for medical expenses and indirect costs that correspond to lost output. Willingness-to-pay measures the resources individuals would forgo to reduce a risk of death or illness.

Each method has limitations and is appropriate only for certain applications. Major functions of the ongoing study are to assess the suitability of the available methods and data for providing the cost estimates Congress has requested and to foster improved methodologies and data. In order to indicate the range of possible results within the limits of accuracy of available methods,

> Health costs should be calculated using both output-accounting and willingness-to-pay methods, to the extent feasible. In the first few biennial reports of the ongoing study, estimates of monetary losses due to morbidity and mortality associated with environmental factors should be presented using a range of fixed values drawn from existing studies for cost per death, cost per day of illness, and cost per year of life lost.

An illness or disease can result from several independent or interacting causes, which may include one or more environmental factors. However, environmental agents may increase the severity and costs of an illness, as well as the number of cases of illness. For example, air pollution may exacerbate asthma. Attempts should be made to determine the proportion of total health costs of a disease or illness that should be attributed to environmental factors if a certain proportion of the cases could reliably be estimated as caused by these factors.

Although the estimate of total national health care expenditures (direct costs) is reasonably accurate, the methods of allocating these costs among diagnoses need improvement. For example, although many patients have multiple health problems, costs are allocated to the primary diagnosis. Consequently,

> An investigation should be made of the difficulties of analysis introduced by the presence of multiple diagnoses.

The committee recommends steps to enhance the data available for estimating direct costs:

> A longitudinal survey of patients in a prospective study of costs by diagnosis should be begun. In addition to longitudinal surveys, cross-sectional surveys of patients to determine utilization and costs of medical care should be considered as a source of information about direct costs and health effects.

A longitudinal study would enable more accurate allocations of direct costs among particular illnesses and diseases and also should provide valuable new kinds of information about the distribution of costs of an illness or disease over an extended time. There is a particular need for longitudinal studies to provide incidence-based cost data (that is, the present and future costs (from discovery until cure or death) of new cases of the diseases discovered during a specified time period), in contrast to the usual cost estimates, which are prevalence-based (that is, give the costs incurred during a specified time period by all cases of a disease that existed during that time period regardless of when they began). Existing data sources also should be used to develop profiles of medical care costs that individuals with specific diseases or illnesses incur. The committee further recommends that prevalence- and incidence-based studies be compared to see how closely prevalence-based costs approximate incidence-based costs in situations where incidence-based costs would be more appropriate. This type of comparison would be valuable because prevalence-based data are more easily obtained than incidence-based data.

For estimating direct costs,

> Net direct costs of illnesses should be calculated in addition to the total direct costs now reported.

Total direct costs are direct costs as conventionally estimated. Net direct costs take into account future direct costs, appropriately discounted, that would have been incurred if the person had not died. Net direct costs of a disease or illness are the total direct costs minus the discounted value of the health costs for other health problems that would have been incurred if the person had survived. Net direct costs are the appropriate measure of direct cost reductions that could be expected if the incidence of an illness or disease decreased; use of total direct costs instead of net direct costs would exaggerate the savings in medical expenditures that could be realized by eliminating some diseases.

Indirect costs include loss of output because of illness or death of the worker. The loss of output for employed workers is measured by their earnings, including supplements to wages paid by employers. To improve the quality of data on indirect costs due to mortality and decreased productivity, the committee recommends that

> New data sets containing personal and job characteristics for workers should be developed. They should include major personal characteristics, health histories, and work histories, including occupation, industry, and firm.

Improved methods for valuing non-market time, including time for housekeepers, retirees, the unemployed, and others not in the labor market, are also required.

Willingness-to-pay estimates depend primarily on two types of data--wage premiums paid for risky work and surveys that ask people how much they would pay to reduce their chance of illness or death by a small amount. The values of willingness-to-pay may be based partly on the same considerations of mortality, direct medical costs, and lost output as output accounting, but also include lost leisure, pain, suffering, and other subjective costs of illness. In principle, all costs that matter to the potential victims are included. However, the wage premiums for risky work assume that workers are fully aware of the hazardous nature of the job. Recommendations for improving willingness-to-pay estimates of health costs associated with environmental hazards follow.

> Wage data used in willingness-to-pay estimates should be improved.

According to economic theory, the appropriate measure of risk premiums should use after-tax wages rather than before-tax wages. However, information related to gross wages also should be available for other types of calculations.

> Surveys should supplement the use of market-based studies in estimating risk premiums paid to workers.

The committee proposes that, after identifying to the extent possible the diseases and symptoms caused or exacerbated by environmental hazards, the ongoing study should include surveys to assess the willingness-to-pay to avoid the health effects. Health effects of concern might include acute and chronic respiratory disease, angina, or death from a specified disease.

Pain and suffering that accompany illness and disease can lead to a variety of psychosocial problems such as reduced self-esteem, social isolation, and emotional problems for the individual and the victim's family. Although some recent attempts have been made to evaluate these by the output-accounting methodology, surveys of willingness-to-pay seem at the moment the most promising method for measuring costs of pain and suffering.

> It is recommended that questions be added to surveys to determine if they yield consistent and reasonable answers for valuing pain and suffering. Any approach to the measurement of costs of pain and suffering must be regarded as a research problem at this time.

Conclusion

Although the cost estimates that Congress has requested cannot be obtained with precision soon, attempts to obtain such estimates can be helpful in making decisions so long as the assumptions, limitations, and uncertainties of any estimates are clearly indicated. The ongoing study provides a unique opportunity to evolve new methodologies and to focus and coordinate widely scattered efforts to determine the health benefits associated with improvements in the environment. These efforts should enhance our ability to prevent health problems associated with environmental factors.

Mr. **Walgren**. The next witness is Dr. Marion Ball, director of computer systems of Temple University Health Science Center. Dr. Ball comes to us with a broad background in computer medicine. She is the president of the Society for Computer Medicine. She has lectured in areas of hospital information systems, laboratory computing, and computer usage in medical education.

At present, Dr. Ball is director of the computer systems at the Temple University Health Science campus. She is also an associate of the department of medical physicians and served as a consultant to a number of governmental agencies.

We certainly appreciate having access to someone with your experience, Dr. Ball, and we would be happy to hear your testimony. If you have a written statement, it will be made a part of the record, and please feel comfortable to summarize or proceed as you wish.

STATEMENT OF DR. MARION BALL, DIRECTOR, COMPUTER SYSTEMS, TEMPLE UNIVERSITY HEALTH SCIENCE CENTER

Dr. **Ball**. I was given three specific questions to respond to which I will address. I do have a written documentation which is available to all of you.

I also have a fourth issue I was not asked specifically to address, but I would like to share it with you as an overall concern in the area of this committee's interest.

The first question I have been asked to address is as follows: Assuming there is a need in developing a coordinated health information system, is the current computer technology available capable of addressing this task?

To answer that particular question, I think there is no question that the technology that exists today in 1981 can address the issues that I understand to be a coordinated health information system.

I think, much more than a hardware issue, as to whether we can do on-line data acquisitions, is the question whether the technology is capable of providing data to the physician where he needs it, for patient care. Also this goes for the whole area of the allied health professions which we haven't addressed today. I listened with great interest to what Dr. Lashof and her associates talked about and that really emphasized the whole area of health statistics and research components.

You will see that my interest is much more in the area of actual patient care, the involvement of the physician as he provides care, the whole area of aid to the patient and how we can link all of these elements together with existing technologies and softwear that we have.

First of all, having said that technology isn't a problem, let me, however, put a statement before you where I think some of the problems are, and those are in the whole area of overcoming resistance to technology, overcoming the whole telecommunications problem, and accepting computerization into a very stayed environment. Mr. Brown touched on this issue earlier.

I will mention eight major areas—I have also provided additional information and discriptive handouts in your packet.

Even if we were just to look at the problem of overcoming the fear—of technology and telecommunication—we first have to overcome the oversell by the vendors who promise more than is possible.

Second would be the recipients' unrealistic expectations of what can be done. The third one is changes in the traditional procedures of medical practice, a very important aspect. The practicing physician will have to come to grips with how the technology is integrated into their existing disciplines.

Fourth, the insufficient medical professional involvement in making decisions as to what type of technology needs to be used or what can be done to integrate it into practice.

Fifth, improving "old systems" versus shifting to new paradigms. This affects the whole area of changing from what we are doing now to what can be done in a new technological environment. We have seen this in many other areas. The airline reservation systems have changed traditional ways airlines have run. We have seen the stock exchange and how that has changed by using the large national networking systems. Those are the types of changes we have not seen at all happen as yet in the health area.

We have the fear of leaving the written page, or the "Gutenberg culture," which is a term coined by Dr. Gabrieli.

One crucial change is the whole metamorphesis that will have to come about in today's medical education, the curriculum that is currently being used in training our future physicians. This will impact the use of technology and working toward a coordinated health information system.

Then, of course, the last question, just the overall fear of the unknown, not knowing what impact the computer will have on practice of health care in our country. I think many efforts are directed into how to overcome these things. We have activity in the National Library of Medicine which, in my opinion, has been the leader in providing the change agent's role in trying to bring training programs into existence, for bringing physicians and computer scientists together in 10 training programs that NLM is funding and has funded over the last several years.

NLM has also worked in the technological aspect of seeing how we can put together an advanced terminal system where one terminal will have access to many different types of data basis. This is addressing some of the issues you are trying to look at present.

This would be an answer to the first question which was asked.

Now, the second question I was asked to address is the following: Are there existing medical information systems that would be useful in the development of a coordinated health information system?

Here again, I think the work, at Stanford's SUMAC system—which is probably the center of artificial intelligence development—has done in developing data bases for the retrieval and storage of basic medical information, an example is the antibiotic therapy system called Mycon.

Also you have the work done at Pittsburgh by Dr. Jack Myers in the internist program where he has coded and has accessible all internal medicine diseases, when operational access could be given to physicians in small rural areas, in emergency rooms, in the areas that might not have access to the physician. Here a computer can provide assistance to the intern or resident.

We also have the Aramis system developed by Dr. James Fries, in California.

Cardiologist—a very find system developed and updated for epidemiological research activities at Duke University.

The Hepatitis system is a large data base developed by the National Library of Medicine and is under the direction of Dr. Lionel Bernstein. Cardio-Praktice, developed by Dr. Gabrieli. Also an assist program called Help at Latter Day Saints Hospital, developed by Homer Warner.

These are just a few examples. Many additional ones are in the supplementary information I have provided.

I think in the whole area saying the question being, what exists and what could be tied into something of the coordinated health information system, yes, there are hospital information systems existing which already share and are using many different types of systems. There are some very sophisticated installations, ones which we call level 2 systems; some less sophisticated ones, level 1 systems.

The data bases I referred to earlier were funded and developed through Federal funding. Most of the ones I will mention now, as far as hospital systems are concerned, were developed by the private sector. Systems such as the Technicon's Medical Information System, originally developed by Lockheed Corp.. Then you have additional systems developed by Burroughs Corp. Datacare, which is a company using IBM equipment; Spectra Systems, IREC. Many different private sector information-hospital information systems, which could be looked at if we looked at some kind of coordinated system.

To go to the third question you posed to me, it reads as follows: "Would the development of such a proposed coordinated health information system significantly alter information flow in the hospital?"

Well, there is no doubt about that. Once you use technology of the power and the impetus which computers can bring, the entire way that health care will be managed will significantly change. I think this has been seen in hospitals on a very small scale, if you wanted to look at it—since we are comparing it to a global system here—a hospital running under a computerized hospital information system has a completely different way of management than we have in the traditional manual systems.

It is a revolutionary thing that happens to a hospital when a computer is installed. It is very trying at the beginning, but in the end, it has vast advantages which has now been shown.

Mr. SCHEUER. Is part of the reason for this very disappointing lack of action in the last 4 or 5 years accounted for by the fact that the hospital managers or doctors/hospital managers perceive this as a threat and don't like it and are holding it at a distance?

Dr. BALL. I think your point is well taken.

Mr. SCHEUER. I am not trying to make a point, I am asking a question. I don't want to put words in your mouth.

Dr. BALL. You don't need to, sir. I think this is certainly a phenomenon.

The other side of the coin is, there is realization that without a complete reorganization and a reevaluation of manual systems needed to lead to computerization, change is inevitable. And over the hill, after the effort is made, there is enough reward that that is the direction in which hospitals are going to have to go.

Part of this is the resistance I mentioned earlier. It is fear. It is a lack of effort being made to educate the hospital administrator and the physician to the importance and the value of these types of systems.

In many ways, I think a good analogy would be, within the last couple of years, installing a hospital information system was relegated to the same kind of thing as putting in a new elevator system or a new air-conditioning system. It is not of that ilk at all.

It has implications from the top point of administration to the entire lower levels of running the hospital administration.

What we are now finally seeing is that top management is getting involved in making decisions as to what systems should be installed; is getting involved in bringing their various ancillary people into helping in the decisionmaking process.

The fact is, the shockwave has been felt and action has been taken, and those hospitals that have gone into computerization would never want to go back to what they had before. So that is the other side of the coin.

But then, if you look at what exists—I have some tables in the material submitted.

Mr. SCHEUER. What percentage of all hospitals have gone into computerized management and control systems?

Dr. BALL. I wanted to divide that up into several areas.

In the area of financial management, I would say a good 70–80 percent have gone into using the computer in the billing, accounts payable and, let's say, the whole financial aspect.

In the area of patient care where we go into hospital information systems, where we look at admission, discharge, transfer systems, order entry results reporting, we have two definite levels of staffication. We have the one communication of sending orders out, and even that is small, I would say, percentagewise maybe 30 percent of our hospitals are looking at using these systems. And the more sophisticated ones, the big ones like the Technicon Medical Information System.

I would say there are not more than 200 or 300 hospitals in the country even getting involved in that, let alone being installed.

We realize we have 7,000 hospitals in the country of various sizes, so the percentage is very small. Looking at those that are doing it, the curve is exponential as to the use of computers in the health care environment in hospitals because of the successful experiences that are not coming into the forefront when well managed, when well installed, and when realizing what the advantages are, plentiful, particularly in the cost savings area.

That is the bottom line. They are realizing, finally, that initially it is going to cost them more to put these systems in, but over time, they have shown that costs will be reduced. They can treat more patients and treat them better without adding more staff, more nurses, more admissions officers, et cetera, and more people in the laboratories.

In many ways, the use of computers in medicine has been a retarded field. We are way behind in the use of computers compared to the oil industry, the airline industry. For the use of this technology and health care, we are 5 to 7 years behind other industries. I think we are now slowly starting to catch up, but we have been slow, there is no doubt about that.

Mr. SCHEUER. I did not mean to interfere with your testimony.

Dr. BALL. It is on line real time.

I want to come to the one question which has brought significant changes in information flow and part of the discussion was carried out in your questioning.

In the testimony which will be available, we have the names of individuals who, I think, have worked in this area, have done some excellent work and even looked at what coordinated information systems are capable of.

In my particular knowledge, the work Dr. Rudi Bickel has been doing, I have had dealings with him as one of the brother or sister organizations, and I am most impressed with the kinds of issues and problems they are facing since they are really looking at how we can provide coordinates systems among the three services. I am interested in that because if we can do someting in the three services, then let's see if we can look at the whole country.

We have people like Dr. Lindberg, Dr. Gary Hammon, Dr. Gabrieli, Dr. Barnett, Dr. Weed, Dr. Elschepp. All these people are expert in having addressed some of these planning issues on a national basis.

Now, to the fourth question that I am going to ask myself, because I think it might be of interest to you as well——

Mr. SCHEUER. Is that still on line?

Dr. BALL. This is on line real time, absolutely. Please interrupt if you have a question.

That is something we haven't realized that byproduct of such a coordinated medical information system could provide.

One of the things that we look at in our country is the competence of medical care and the whole evaluation of how our patients are treated by our current physician population. We have all kinds of mechanisms at the moment to try to evaluate how well our people are being treated. We have the PSRO systems, we have retroactive review processes within the hospitals. And, in effect, what we do when we do retroactive review is give the physician a closed-book exam through the entire process of treating the patient.

He is evaluated 3 weeks later in a medical review meeting as to whether he did the right thing for the patient while the patient was in the hospital. The physician doesn't benefit, the patient doesn't benefit, because it is 3 weeks later.

Where it is capable and where I think we will see an enormous change in the practice of medicine is, when we use on-line realtime hospital information systems. With this we finally have the capability of giving the physician information when he needs it and where he needs it, which is at the bedside of the patient. We cannot do that without the current form of technology.

We can, through good medical education, through the National Board of Medical Examiners, evaluate what the physician has in his head. We can give him a multiple-choice examination. We can say, yes, this man or woman is capable to practice medicine.

What we cannot tell at the moment is whether what the physician has in his head is being applied to the practice as he cares for that patient. That linkage we are not capable of doing, using the current technologies that are in existence in most environments—which are the manual systems.

Through use of computers, we will be able to provide the physician with immediate feedback on what he is doing for his patient. We will provide him with an open-book exam and say,

> Look, here you have just admitted this patient, you have ordered these tests. We know from going back to the latter report from statistics that these are the types of things you might do.

You have a guy coming in with appendicitis. Why didn't you give a white blood count request to the laboratory? Why does he have to have his wrist slapped 3 weeks later when it comes up for review? Tell him right now. Now the patient can benefit from it. Now he can increase his own capability to practice medicine. We don't have to have examinations for recertification, relicensing, and all of the continuing medical requirements that are being placed upon us.

This is when you say we must look at this system or this computer as a new thing, as something that has a national implication. If we can bring national data systems to the attention and to the hands of every practicing physician in this country—where he has a terminal in his office, he has a terminal at the bedside of the patient, that is what technology can do and that is what we are not doing now.

Basically we must ask the question properly. Maybe that is where we are at present. Just as Max Plank said when he was asked how and why he got his brilliant physics enlightenment for which he got his Nobel Prize, he said, "Ladies and gentlemen, in the correct formulation of the question lies the key to the answer."

I think where we look to you and you look to us, it is, what are the basic questions we must address. Are we going to have the clout to impact medical education? We don't need physicians anymore who have fantastic memories and who score the highest on chemistry examinations and on their physics or whatever. We can go back to looking at the humanistic aspects of physicians because finally we can extend their memory by giving them a computer to help the memory.

Just like the age of technology before the automation. The car improved our ability to get from here to there more rapidly and more efficiently. We didn't have to walk everywhere, we extended our muscles.

In these areas, we are not talking just about minimal things. I think we will change our whole health care delivery and we will be getting back to the patient, we will be caring for the patient, we will be able to give more of a humanistic approach to medical care, which I personally think is sorely needed in our country.

I am glad to answer any questions.

Mr. **Scheuer**. We are really giving the doctor more than an open-book exam. We are giving him an open computer exam. That is far different. You are giving him not only a great big tome, but you are giving him instant retrieval of exactly what he has to know so he doesn't have to thumb through 1,200 pages.

I remember taking open-book exams in college and in law school.

Here, I presume, you can punch out exactly the question and get the facts that have to be factored into the decision, and the computer, out of millions or billions of pieces of information it has stored away, it will come out with the answer.

Dr. **Ball**. It can do it faster than we can turn the pages. We are using it for what it should be used for, speedy recovery and pinpoint information. It is much better than the open-book exam. I will remember that for my next lecture.

Mr. **Scheuer**. I hope you will quote the U.S. Congress as having given you the idea.

Dr. **Ball**. I will.

Mr. **Scheuer** [presiding]. Congressman George Brown.

Mr. **Brown**. Dr. Ball, it is obvious from your statement that you feel the technology, the systems are available to provide all of the information that is reasonably necessary to develop an improved national health information system.

I would like to know what you feel are the obstacles or what are the steps necessary to overcome these obstacles to make a substantial improvement in the present system which obviously is not making full use of the capabilities that we have today.

Where do we grab hold of this problem in order to do something about it?

Dr. **Ball**. I think one of the areas we could start in is to look at the basic standards that need to be established, just as we did in earlier times when we established that we should have railroad ties that should all be the same width so we can travel on the same track from east to west and from west to east.

We have no standards with regard to major data bases. We don't have at the moment the type of standards we would need in languages these various systems are being developed in. We could do a lot with regard to making some kind of mandates of at least requiring that one type of a data base can—even if it is through a translation system—speak to the other.

The point that you have 300—I think that was mentioned earlier—different types of bases, just with the Federal Government, for reporting various types of health care statistics is a tragedy if there is no vehicle or mechanism for these to be able to interact with each other and be linked. This is something that I think is a big problem.

Also, I think one of the advantages that we have seen now in costs going down, which is rare in our country, in hardware, that we have the whole new development of microprocessors, which now makes it feasible for every physician, even every person to have a home computer.

What kind of standardization do we have there? Should we look at what kind of disks they have that at least have some compatibility, the same thing we did with the record industry? If we have a cassette that can be used in one tape recorder—maybe not even one standard, but four or five acceptable standards.

I also mentioned earlier there has to be an asserted effort to relook at our medical curriculum. I think we need to desperately give our upcoming physicians an advantage to have computer literacy in their medical education so that when they are health care providers, they will no longer be fearful of tapping into what the National Library of Medicine can give them at their desks.

What the SUMAC system in Stanford can give them on arthritis, on hepatitis, on antibiotic therapy, on the myriad types of data bases that are existing already. A lot is education.

I think we can do a lot with the mass media. The mass media, up to now, in many ways has oversold what computers can do, making it very difficult and making the expectations of a 100-percent solution the only way. In those things, there are not 100-percent solutions.

For example, the EKG analysis. For a long time, we could use the computer in the EKG area to determine between a normal reading and an abnormal reading. Obviously this is an intensive and expensive operation to have a cardiologist spend his time reading EKGs. About 60 percent of the readings are normal. If a computer can take over that task, why don't we let the computer take over that task and concentrate on the 40 percent where the computer doesn't have that kind of sophisticated software developed as yet. Not to say it is not coming. In many cases, it was washed away completely because it couldn't do the entire job. We often didn't want to accept that there was help in the 60-percent area.

This I blame on oversell of our private sector vendor world that promises the Moon rather than promising one or two stars and saying this will help and work in the right direction.

Those, I think, are some of the obstacles, besides some of the others I mentioned in answer to the first question, Mr. Brown.

Mr. **Brown** [presiding]. Mr. Weber, have you any questions?

Mr. **Weber**. Yes, I do.

First of all, I find your testimony very interesting. Let me apologize for the nasal tone of my questions. I have a health care problem of my own.

It occurs to me, as I listen and hear you talk about more efficient use of personnel and the ability to care for more patients with less personnel and the obvious retraining of personnel that will be necessitated, is there a lot of opposition to this idea from the established medical community, whether it be unions or the AMA or whoever else may be involved?

Dr. **Ball**. This, I would say is not an easy question to answer. When we talk about health care, which we are doing here, we are encompassing so many different professional groups. I would say, let's look at who is actually using it and use that as a measure.

I would say nurses, for example, who provide to a great degree most of the actual caring for the patient as the patient is in the hospital—of course, under the direction of the physician.

In those cases, the physician still goes about his ordering process, writing on his order book in exactly the same fashion he has done before, but instead of the nurse carrying it out and filling out a requisition form for the lab and a requisition form for the radiology department and for the pharmacy department and for central supply, he or she is the one. The physician himself is the one who will utilize technology and be able to go to his or her terminal at the nursing station, put the requests in, verify it again, in real time dispenses the information to the ancillary areas, in a time-frame that is out of space compared to the way it is done manually. Manually one has to wait for a courier, four slips, one to go to the business office, one to insurance,one to lab, et cetera.

With a HIS everything is done on line. In the nursing area, not only is there not resistance, but people working in hospitals with HIS are converts, like converts who are pillars of the church.

Mr. **Weber**. Is that a trend that will probably hold true, that the personnel below the level of physician would have their role substantially enhanced?

Dr. **Ball**. At the moment, yes.

When we look at technology, until, in my opinion, voice input, which is also not that far off, is available, the physician will not input via keyboard, what he would consider to be a clerical function, the information directly into the system.

However, I think not until he does that is there full-circle responsibility because then he is finally in touch with the technology, it is then and only then when technology gives him back at that particular point, as he is ordering, information and say to him,

> You just ordered digitalis. Did you know that 3 days ago the latest journal in the New England Journal of Medicine said for this particular ailment, digitalis is only the third choice? We have found that this drug is better.

What does he get? Realtime on-line continuing medical education. This not only benefits him—because what do we want? We want him to have the knowledge when and where he needs it so he can benefit his patient. That is the point at which we will have the ideal and we are getting there very rapidly.

The number of physicians now using microprocessors and computers in their own office practice is growing astronomically and it is very exciting. But how do we control all this? Who is going to be responsible to see that the information that is computerized is indeed the valid, responsible information that is checked off by the American Radiology Association or by the pathologists, and so on?

So there are all kinds of complications that you will hear more about later on that have to be checked. But your point as to when it is used: Now it stays at the allied health level and is doing well. The physician is the next step.

Mr. **Weber**. My district has many, many small health care facilities in rural areas, and I can see tremendous advantages.

What about cost, though? Will the small facilities run into problems in terms of the cost of hooking into a system like that?

Dr. **Ball**. In my opinion, as far as small facilities being able to interface into large data bases will probably have the greater advantage. Let's say in a small emergency room, in a rural area where your constituency might be, it might be that if the resident who is running the emergency room can call, via terminal, into a poison control system—a child comes in and the mother says he just swallowed a whole bottle of clorox. What should the doctor do?

He can get that information, and responsible information, better than he could looking through 5 or 10 books at the moment and have that expert opinion right there with him on-line realtime by using a telephone accessible data bank.

So, for the smaller areas, I think we will see tremendous advantages, at the cost of a telephone line and the rental of the terminal.

Mr. **Weber**. And the training of the personnel?

Dr. **Ball.** If the physician had this type of training as he came through our 120 medical schools, it is no issue at all which he uses. At the time he will use it in the same fashion he picks up a telephone or the way he uses his stethoscope.

We have to attach the problem on every level.

Mr. **Weber.** There are probably a lot of medical personnel out there who would need some retraining, at least in the use of the technology.

Dr. **Ball.** Most of them.

Mr. **Weber.** Thank you very much.

I have no more questions, Mr. Chairman.

Mr. **Brown.** Dr. Ball, may I ask another question as long as you are available here?

You made reference to the TRIMIS system, or the development. I am not very familiar with it, but I recall it was the subject of oversight hearings by the Government Operations Committee which seemed to find there was a lack of direction and focus on the development of that system.

I don't expect you to have a familiarity with that and we should have other witnesses who can comment, but since you mentioned it, I just wanted to give you the opportunity to offer any comment that you might have, as an informed layperson about what happened in that particular effort to develop a better utilization of data systems within the military hospitals.

Dr. **Ball.** Let me address the aspects of it that I can. You are right, I have no knowledge of the overall political ramifications, and so forth.

What I wanted to say when I mentioned TRIMIS before, is we have some very responsible and capable people who have started to address the kind of major problems inherent in looking at a coordinated health information system. And the kind of problems that they have run across and the kinds of things they have addressed I feel have been very responsible, and sometimes being able to show what cannot be done is as important as what can be done.

So in this rapid—and I again go back to just the one individual with whom I have had most of my contacts, and that is Dr. Rudi Bickel. He will be testifying, I see, on Friday, and I would feel he could probably address the kinds of problems you are asking, more adequately.

Mr. **Brown.** We will refer this to him.

I mentioned this because you indicated standardization might be a major problem, standardization of technology, and so on. From what experience I have, it seems to me that the problem which seems so simple is a tremendous problem.

I recall, over a period of several years, being familiar with an effort to standardize terminal keyboards for the industry. I am not sure they have succeeded yet. Terminal keyboards would seem to be one of the most obvious things.

Could you comment on the difficulties of achieving standardization?

Dr. **Ball.** I think you are right on target in that this is one of those horrendous items that make tremendous commonsense. Perhaps we need to start with some very, very basic things. Talking about successful things, for example, the language COBOL, common business oriented language, which is probably even now the language in which most business applications software is developed in.

It has got finally, after many, many trials and errors, a standard. There is now ANSI COBOL, a national standard COBOL. Having that language standardized, even though it still requires certain changes if you use it on an IBM piece of equipment, or Control Data, or Univac, the fact software now developed can be used across the board has saved so much money for, let's say, a hospital that has in existence a Honeywell piece of equipment and wants a piece of software that has been running on IBM equipment, if it is written to ANSI COBOL standards, this piece of software can much more easily be transferred. Again, it is a cost saving in the end, if we can force a certain amount of minimal standards.

As I say, why is our country so super in the telephone world? Because we have standards in our communication requirements for the telephone. That doesn't mean there are people in the private sector in there, and we don't have Government users.

I have a special little card that I use, as my children are in college and I wanted to see how I can reduce my telephone rate. I have "City Call." I can use my little telephone, which is developed for the Bell system, and I use that telephone on City Call by putting in a certain code and I can use that network system, if you like, to call my children for 20 percent less because I am taking advantage of that.

That wouldn't be possible if we didn't have a standard on telephones.

We have the same situation with the railroad, early on. The same type of standards we have in interfacing data phones from one computer to talk to another computer.

Another example, we have one language. I mean we have standardized and said that English is the language. I think that is one of the reasons this country is so strong. We brought people from all over the world, and we are a new country. We have background from everywhere. You might have a German background, you might have a French background. You might have a background that is a third and your grandparents know another language, but in our school system we had to speak English. That has brought us together, unified us, and made us strong.

If you think of language, it is a perfect example, that we have to get our act together in order to maximize the use of computers in a coordinated health information system.

Mr. **Brown**. Thank you, Dr. Ball. I have no further questions.

Mr. **Weber**. The point your are making is germane not only to health care systems. Doesn't your answer refer to the entire computer technology area?

Dr. **Ball**. Certainly. It has implications to the entire development of how we use this powerful tool.

Mr. **Weber**. It is a rather far-reaching statement, then, if you talk about some standardized and presumably regulated approach to all computer technology.

Dr. **Ball**. Again, as I said, we need to first come to the point of formulating the questions. What is the ultimate goal we want to address? In other words, we want to plan our flight so that we can fly our plane.

What I am suggesting is that these are some of the major issues we need to address. We look to people of your expertise to guide the country, telling us how you feel that we might be able to fly this plane most effectively and most efficiently.

Mr. WEBER. Thank you.

Mr. SCHEUER. I would like to follow up some thoughts Congressman Brown was expressing.

You said that only 2 or 3 or 4 percent of the hospitals of the country have really put in place a comprehensive health information system. We are trying to expand that.

Would it make sense for Congress to take the military and lay on them certain further requirements to conform to a standardized health information service? It is a command organization, used to following directives. Whatever reservations there might be, when there is an order, it is an order.

There are a great many threatened egos in the medical field. Would it be good for us to use the military in the next few years as our universe, trying to get a comprehensive health information service, universally installed in our military hospitals as a sort of a model? Then the rest of our hospitals could follow.

Would that be a useful next step or is there some other next step that is indicated?

Dr. BALL. I think that is a very viable next step. It could be used as an experimental ground. As you say, you have control of the military hospitals. Why don't we have three of the military hospitals work on a laboratory information system, A, B, and C, work on those in the three environments, see which is best. That which works best is the one we put in all the way. We have never really compared and looked very well at comparative systems to do specific jobs.

The clinical laboratory computer is an excellent example of major failure over the last 15 years: 10 years ago, there were 14 companies that provided viable clinical laboratory systems to our country; today, there are 2 of those left and they are in a completely different form.

The fact of the matter is they do not come up to the standards of what pathologists wanted. They were developed by engineers, they were developed by entrepreneurs.

There is a paper in the collection of papers I gave you on this. That is an example of where the military hospitals would have a perfect testing ground to say, these three systems are going to be tested, we are going to have each of the private sectors which provide these systems work on these for 2 or 3 years. May the best one win. If this system works well and meets the needs, we will put it into all of the environment.

Your example to use that as a testing ground, I think, would be a most workable way to go about it, and I would like to see that, personally.

That is where our effort should go.

Mr. SCHEUER. We are all troubled by the lack of progress. We are trying to get a handle on why nothing seems to have worked very well. We did pass some amendments in November of 1978 to the

Public Service Act to secure uniformity in the registration and collection of mortality-morbidity and other health data. We required the Secretary of HEW, now HHS, to establish standardized means for collection of health information and statistics and to establish standards to insure the quality of health statistical and epidemiological data collection processing and analysis. It goes on. Yet nothing very much seems to have come out of the hopper. We keep shoving mandates in there and we meet a great silence. What do you recommend from your experience that we ought to do to further encourage the production of a viable health information service and then encourage more hospitals and more health related institutions of all kinds to start using it. Not only tertiary hospitals but also community hospitals and HMO's and nursing homes. Would that not have to be done in order to get statistics at every level of sophistication and intensity of health care? Can we then determine for a particular person at what level that patient ought to be plugged into the health care system, what is the minimum necessary level of sophistication and elaboration of services and support system that patient needs? If what the patient needs is just occasional access to a doctor or a nurse and mostly maintenance service, if it is an elderly person, they might take care of themselves. There is no point plugging them into a teritary hospital that costs $300 or $400 a day. They can do with a lesser level of intensity of health care. Would you not need some kind of computer analysis of costs and of patient care needs at all levels of the health care system in order to compare costs of treating patients of equal levels? At different levels? Could the computer, which would have information about all of the systems and would be given information about this particular patient's spectrum of needs, then tell us whether the patient should be plugged into the system? How do you move forward even incrementally. We are very frustrated with the snail-like pace of the progress. What should Congress do?

Dr. BALL. I think the point that you made a few minutes ago, what I called the evaluation criteria of systems. The one example we both seem to agree on or discuss is maybe use the military hospitals as an example. I certainly do not want to imply that should be the only arena in which it should be done by any means. I think there is a vast necessity for the private sector to get involved in not only providing but in evaluation types of systems. Some of the Government agencies have looked at studies, particularly on cost data—"Battelle Report" that is available on how much does it cost to run hospital information systems computerized as compared to manual systems and that information of course is available. I think in many ways rather than trying new things there is so much in existence already to let us look and see how successful they are. You mentioned the whole area of health maintenance organizations. A lot of money has been pumped into it but what we have not done is see how effective are those kinds of data systems. What about them is good? Is it easier to access that mode of patient care than going into an emergency room in a normal hospital? The problem is enormous. The way you outlined it I thought was superb and your question was how do we go further. We do have to look and examine evaluation on all of these levels. I think your discouraging comments that we might not be moving as fast as we would want, I think to give a ray of light I think we are moving a little faster within the last 2 years. I think the amount of technology that we have seen just recently come into being and maybe with the emphasis on health care over the last couple of administrations that we are starting to look at cost saving. We are starting to look at how we can reassess the way we treat our population. As you were saying they are looking at even more data systems that are developing to address health maintenance organizations. The cards are not in on that. It might not be the solution but let us look and let us say where are we now, what has worked successfully, what should we push more actively than the other areas. I cannot answer all those questions. I do know in the hospitals I work in and the ones I do consulting for, those that have gone into relooking at their manual systems, have started computerization, have not regretted it when they have done it with top administration support and with careful assessment and are going in the right direction. I think technology is here to stay. It is a matter of how do we use it most wisely and how do we use it to the betterment of our health care. Those are some of the questions we do not have answers to yet.

Mr. SCHEUER. It seems to me there is a self-selection process. Where you have top administration that is sympathetic to moving into the future they hire you as a consultant and they move into the whole new computer age. The question is how do we induce more officials at the decisionmaking level in the hospital, these top administrators, to retain the services of a consultant such as yourself to move into this computer age?

Dr. BALL. All I can say is I am doing my part. You are right as far as on a national level, I think partly they will be seeing that those hospitals that are computerized maybe eventually will be having more money available to do what they want in those hospitals to provide better care. I think eventually we will see that hospital A and hospital B will say with their tools they are digging a better ditch than I can dig with so I will see if I cannot get the same shovel to make my hole just as good as that guy's hole. That is one of the ways. But your question is excellent. I just cannot give you any more of an answer than to say that is where the emphasis needs to be. Being an educator, I think one way to do it is by education but sometimes show and tell is more effective. We will have to wait and see.

Mr. SCHEUER. Is there evidence now that hospitals who move into the computer era are able to contain their costs better without sacrificing patient care? Is the doctor able to perform at a higher peak of effectiveness having his memory, imperfect as human memories are, constantly being buttressed and enhanced by his computer capability? Can we prove that doctor has an enhanced capability and that that hospital has an enhanced capability to provide better patient care, more comprehensive patient care at a lesser price presumably?

Dr. BALL. I would like to agree with that.

Mr. SCHEUER. Can we prove that now?

Dr. BALL. Yes, I think you can go into a hospital that is now computerized and you can see that patient is getting information from the laboratory more rapidly than previously making it possible for the physician to act more rapidly on what is ailing him and we even have some statistics that show that computerization is getting him out of the hospital faster than in the hospital that does not have a computerized hospital information system. That is the business we are in, getting them in, treating them, and getting them back out into the work force as fast as we can. Computerization is definitely working in that direction.

Mr. **Scheuer**. That is what we want to prove. I think if we could make a record that that is so that would help us a great deal. We will be chatting with you about identifying some of the hospitals.

Dr. **Ball**. I will be glad to do that and I can do that. Some of it is documented in what you have.

Mr. **Scheuer**. We will be talking with you. Mr. Weber I think has another question.

Mr. **Weber**. Following up on one of the points Mr. Scheuer was getting at in his frustration on the pace of progress in this field, you said there has been more movement in the last couple of years. Can you break that down and explain how fast this service or practice is coming on line.

Dr. **Ball**. I would say if we look at just the level one hospital information system. These information systems handle the financial aspect of the hospital, the administrative, discharge, transfer, and order entry functions. Just leaving it at that, within the last 2 years of all the hospitals that have them about 35 percent were installed during that period of time. Before that maybe 4 or 5 percent a year. So within the last 2 years we have had a tremendous climb in the realization of hospitals that yes, they must computerize and they have done that by showing this by buying these systems. You can go to vendors such as McAuto, such as Technicon, and they will be able to show you that within the last 2 years they have sold more systems than in all the time before so that would be an indication.

Mr. **Scheuer**. In the last how many?

Dr. **Ball**. Two to three years.

Mr. **Scheuer**. Then maybe something has happened.

Dr. **Ball**. I think we are seeing a real upward swing because finally it is catching on and they are saying by gosh we have it. There is something to this and we are going to be able to make progress.

Mr. **Weber**. I am not familiar with the schedule of witnesses that are going to come before the subcommittee. Are we scheduled to have some of the vendors testify?

Dr. **Katz**. They will.

Mr. **Scheuer**. When we have vendors selling their different wares to the hospitals is there communication between those systems? Let us say hospital A has one vendor system and hospital B has another vendor system. Are they standardized in that we can compare costs and effectiveness of health care treatment and compare apples with apples and not apples with oranges? In other words do we have one standardized universe even though we have separate vendors selling their separate systems?

Dr. **Ball**. Not exactly but a little bit. If we are looking at how much does it cost you to computerize the financial system using an SMS approach and a Technicon approach both of those companies can tell you how much it is costing that hospital to buy that particular service on that basis and they can say I am including this general ledger accounts payable, accounts receivable and billing so in that regard you do have a base line but whether these two companies exchange data or interact with each other, no, they do not.

Mr. SCHEUER. I do not say whether they do, I say could they or could somebody on top, could HSS if it wanted to compare the effectiveness of these two hospitals and compare how many patient days on the average do they keep an appendicitis patient or a tonsillectomy or whatever? Could they compare their average term of postoperative care, their average number of patient days per operation, and the average number of support personnel per hospital bed? In other words are these systems compatible so that somebody could look at all these hospitals perhaps with their diverse systems and compare the cost-effectiveness of their treatment, the excellence of the patient care, the degree to which patient care reflects use of computer data base and analyzing the diagnosis or helping to perfect the diagnosis?

Dr. BALL. In as much as they are addressing the same issues they can. To a great deal. There might be variables that one is picking up that the other is not but you could look at these two bases and make a reasonable comparison to some of the issues you just asked. In effect the MAPPAS, medical record type of systems that come from every hospital, at the moment do do that. You know exactly for one hospital how many appendicitis cases we had, because it is reported to an agency now. How long was the patient in the hospital that had this kind of hospital information system as opposed to this kind of hospital information system. That kind of data you can get, yes, sir.

Mr. SCHEUER. I am getting constant nudging from staff that we have run way over time. That is a credit to the stimulating and thoughtful quality of your testimony. We are grateful to you. We will be chatting with you about seeing if we can get some documented cases of how hospitals demonstrably have improved the quality of their patient care and have improved their cost-effectiveness by the use of these systems. We thank you very much for your splendid testimony.

Dr. BALL. Thank you for inviting me.

[Questions and answers submitted for the record follow:]

Marion J. Ball
June 2, 1981

Question 1.

Assuming there is a need in developing a coordinated Health Information System, is the current computer technology available capable of addressing the task?

There is no doubt that the question of a coordinated National Health Information System needs to be addressed and the consequent implications carefully planned and analyzed. That the current technology is equal to the task in 1981 is no longer an issue. Computer technology and telecommunications are not the problem. The real issue in addressing a coordinated Health Information System is overcoming resistances to telecommunication innovations in medical practice and administration. Detailed information pertaining to this problem has been addressed by Dr. Marion Ball and Dr. Snelbecker in a soon to be published paper, "Overcoming Resistances to Telecommunication Innovations in Medicine and Continuing Medical Education" and submitted for publication to the journal, Mobius. In this publication the authors identify eight major areas of resistance which are as follows: (1) Oversell by the vendor, (2) recipients' unrealistic expectations, (3) changes in the traditional procedures of medical practice, (4) insufficient medical professional involvement, (5) improving "old systems" vs. shifting to new paradigms, (6) fear of leaving the "Gutenberg culture", (7) medical curriculum change, and (8) fearing the unknown.

Efforts by the National Library of Medicine (NLM) in developing an advanced terminal system is another step forward for transportability and nationwide access to medical information on a national scale.

Marion J. Ball
June 2, 1981

Question 2.

Are there existing Medical Information Systems that would be useful in the development of a coordinated Health Information System?

In responding to the second question, there certainly are a vast number of Medical Information Systems which could be divided into various categories of sophistication and application areas that would be useful in planning the overall development of a CHIS. A collection of articles addressing some of these application areas is herewith enclosed. The systems that should be highlighted, however, are as follows.

In the area of knowledge base systems, special reference is made to the following: INTERNIST (Dr. Jack Myers); MYCIN (Dr. Shortliffe), ARAMIS (Dr. James Fries), CARDIOLOGIST (Dr. Robert Rosati and Dr. Stead), Hepatitis (Dr. Lionel Bernstein), CARDIO-PRAKTICE (Dr. Elemer Gabrieli), and HELP (Dr. Homer Warner).

In the area of Hospital Information Systems special reference is made to the following: Products developed by the private sector (IBM, Patient Care Support System, Technicon's Medical Information System, NDC, Burroughs, Datacare, Spectra, IREC). Companies providing dedicated Hospital Information Systems, shared financial, order entry and ADT Systems of various levels of sophistication are: McCauto, SMS, Technicon, Space Age, HBO, among others, with more details in the enclosed document.

Question 2 Enclosure

WASHINGTON
STAR

12/1/80

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Physicians' New Colleague Joins Search for Human Ills

It was one of those everyday medical mysteries.

A woman entered Massachusetts General Hospital in Boston burning with fever. She was 74, born in Sicily, and had become ill five weeks before — with shaking chills, vomiting and spasms of pain in the upper abdomen and back.

ELECTRONIC DOCTORS:

Computers in Medicine

By Cristine Russell

First of Two Parts

Doctors went about diagnosing the ailment in the traditional way. Later an experimental computer program named INTERNIST, in effect a mechanical doctor, was given a chance.

After a battery of tests and X-rays, the human doctors located a mass in the right lobe of the woman's liver. They diagnosed it as an abscess. Only after an operation did the doctors discover that it was an infected cyst in the liver, resulting from a rare parasitic worm apparently contracted during her childhood in Sicily.

INTERNIST, which later was fed the patient's symptoms, test findings and personal history, sorted through its vast memory. The computer's first conclusion was the same as that of the physicians: an infected liver abscess. Then, after it asked a series of follow-up questions, the computer diagnosed the cause: "Echinococcal" (a type of parasite) cyst of the liver.

INTERNIST "did better than the original doctors," Dr. Jack Myers of the University of Pittsburgh said proudly of his computer brainchild. "They diagnosed the abscess but couldn't figure out why she had it until the operation was performed."

There are about 50,000 specialists in internal medicine around the country, but there is only one INTERNIST.

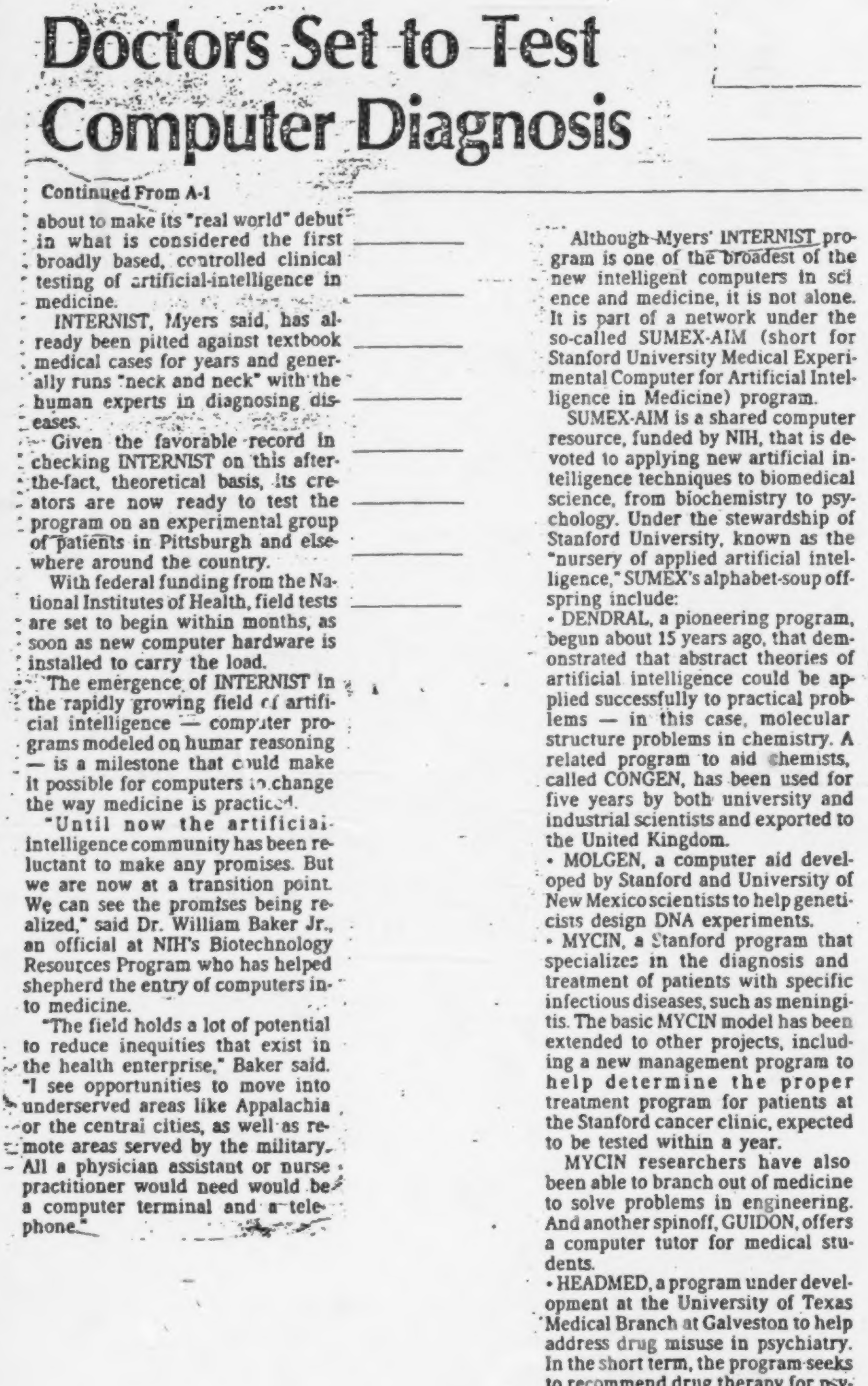
Assisted by an enormous bank of knowledge of internal medicine, this computer program can diagnose a tremendous range of diseases, from a heart attack to Waldenstrom's macroglobulinemia, the uncommon condition that recently killed director-choreographer Gower Champion.

After the symptoms, lab tests and patient history are supplied, the computer searches through its unparalleled memory of more than 500 ailments, narrowing down the possibilities and coming to a conclusion in five to 20 minutes, depending on the difficulty of the case.

After nearly a decade of development, this brainchild of Myers and computer expert Harry E. Pople is

See DOCTORS, A-10

Dr. Jack Myers (white smock) of the University of Pittsburgh and computer expert Harry Pople are the developers of INTERNIST, the mechanical doctor.



Doctors Set to Test Computer Diagnosis

Continued From A-1

about to make its "real world" debut in what is considered the first broadly based, controlled clinical testing of artificial-intelligence in medicine.

INTERNIST, Myers said, has already been pitted against textbook medical cases for years and generally runs "neck and neck" with the human experts in diagnosing diseases.

Given the favorable record in checking INTERNIST on this after-the-fact, theoretical basis, its creators are now ready to test the program on an experimental group of patients in Pittsburgh and elsewhere around the country.

With federal funding from the National Institutes of Health, field tests are set to begin within months, as soon as new computer hardware is installed to carry the load.

The emergence of INTERNIST in the rapidly growing field of artificial intelligence — computer programs modeled on human reasoning — is a milestone that could make it possible for computers to change the way medicine is practiced.

"Until now the artificial-intelligence community has been reluctant to make any promises. But we are now at a transition point. We can see the promises being realized," said Dr. William Baker Jr., an official at NIH's Biotechnology Resources Program who has helped shepherd the entry of computers into medicine.

"The field holds a lot of potential to reduce inequities that exist in the health enterprise," Baker said. "I see opportunities to move into underserved areas like Appalachia or the central cities, as well as remote areas served by the military. All a physician assistant or nurse practitioner would need would be a computer terminal and a telephone."

Although Myers' INTERNIST program is one of the broadest of the new intelligent computers in science and medicine, it is not alone. It is part of a network under the so-called SUMEX-AIM (short for Stanford University Medical Experimental Computer for Artificial Intelligence in Medicine) program.

SUMEX-AIM is a shared computer resource, funded by NIH, that is devoted to applying new artificial intelligence techniques to biomedical science, from biochemistry to psychology. Under the stewardship of Stanford University, known as the "nursery of applied artificial intelligence," SUMEX's alphabet-soup offspring include:

- DENDRAL, a pioneering program, begun about 15 years ago, that demonstrated that abstract theories of artificial intelligence could be applied successfully to practical problems — in this case, molecular structure problems in chemistry. A related program to aid chemists, called CONGEN, has been used for five years by both university and industrial scientists and exported to the United Kingdom.
- MOLGEN, a computer aid developed by Stanford and University of New Mexico scientists to help geneticists design DNA experiments.
- MYCIN, a Stanford program that specializes in the diagnosis and treatment of patients with specific infectious diseases, such as meningitis. The basic MYCIN model has been extended to other projects, including a new management program to help determine the proper treatment program for patients at the Stanford cancer clinic, expected to be tested within a year.

MYCIN researchers have also been able to branch out of medicine to solve problems in engineering. And another spinoff, GUIDON, offers a computer tutor for medical students.

- HEADMED, a program under development at the University of Texas Medical Branch at Galveston to help address drug misuse in psychiatry. In the short term, the program seeks to recommend drug therapy for psychiatric problems. Eventually, its designers hope, HEADMED will be able to diagnose disorders as well.

3

- CASNET, a prototype Rutgers University artificial intelligence program for diagnosing and treating eye diseases — specifically glaucomas. Today, the same approach is being applied in an EXPERT program for diagnosis and treatment of rheumatic diseases, from arthritis to connective tissue disorders.
- PUFF/VM. Researchers at San Francisco's Pacific Medical Center, in collaboration with Stanford, have developed two systems, one for diagnosing and treating pulmonary function, the other for monitoring the condition and progress of patients in intensive care whose breathing is assisted by ventilators.
- RX, a Stanford system for extracting data about the progress and treatment of chronic diseases from existing computer data banks at several centers in the United States. Initial work is beginning with arthritis.

"The whole field is exploding," said Dr. Joshua Lederberg, Rockefeller University president and former Stanford University genetics professor, who helped in the development of SUMEX in the mid-1960s.

Still, the movement of medical programs into practical use has been slow, largely because of the difficulties of translating the loosely organized branches of medicine into artificial-intelligence programs.

Physicians are fond of saying that medicine is as much an art as a science, but computer wizards contend that it is possible to capture and organize the knowledge of medical specialists.

Rather than using the numerical calculations that have characterized traditional computer programming, artificial-intelligence researchers have taken a different approach, called "symbolic computation." This allows them to organize the abstract and largely informal (or "heuristic") decision-making rules used in the real world of medicine into workable computer programs.

The head of Stanford's SUMEX program, Dr. Edward Feigenbaum, called this "knowledge engineering" instead of the "more inflammatory" term artificial intelligence. In addition to practical uses, Feigenbaum said that thinking computers in medicine will serve a broader purpose: demystifying medicine and forcing experts to come to grips with its unwritten methods.

"SUMEX-AIM is eliciting, organizing and polishing a body of knowledge that rarely sees the light of day," the Stanford scientist said. "It is the knowledge that underlies the expertise of practice, the knowledge that is normally transmitted by a kind of osmosis process from master to apprentice. That knowledge will now be codified, taught, used and critiqued."

For this ideal to work requires a unique marriage of computer and medical experts. In the case of INTERNIST, observers agree that the success of the program thus far is a result of the involvement of Myers, an internist whose own broad experience of over 40 years has brought a practical working knowledge to the program.

With his white crewcut and matter-of-fact manner, the 67-year-old Myers fits the stereotype of the old-fashioned family doctor many people wish they had. But his appearance belies a forward-looking approach uncommon among many of his colleagues.

Myers turned to computers after concluding that "no man alone, myself included, knows all the medical information in our knowledge base."

When he graduated from Stanford Medical School in 1937, he said, it was "no problem for the human brain to encompass the field of internal medicine. A smart professor could come on a ward of 20 patients and tell in two hours all he knew. But the knowledge explosion since then has been high."

Concluding that "it's going to get worse, not better," Myers reached for a computer — not only for storing and retrieving medical knowledge, but manipulating it as well. Myers and Pople, a young computer expert, set out to fashion a machine that could think and act like a doctor, taking in symptoms and coming up with the likely diagnoses.

Although they have already programmed knowledge of more than 3,400 "manifestations" (symptoms, lab tests, etc.) and 500 diseases into INTERNIST, the designers plan to complete its repertoire over the next few years. Most the testing of the computer's ability to diagnose cases has been based informally on comparisons with the recommendations of experts cited in case histories in the prestigious New England Journal of Medicine, such as that of the Sicilian woman.

"In hundreds of cases thus far, we do just as well as the experts. But we're still at the stage of research and development," Myers said. He and his federal sponsors believe, however, that the program has reached a "critical mass" sufficient to allow testing on patients.

They will begin on a ward at the University of Pittsburgh teaching hospital and attempt to analyze every case admitted, comparing the findings of the machine against those of the human doctor in charge. "Then we'll provide the analyses to the physicians and house staff and they can do what they want with it," Myers said.

Operating on the old rule that "two heads are better than one," he said he expects doctors will welcome assistance from their learned new colleague.

Tomorrow: The Ethics of Change

FOLLOW-UP REC

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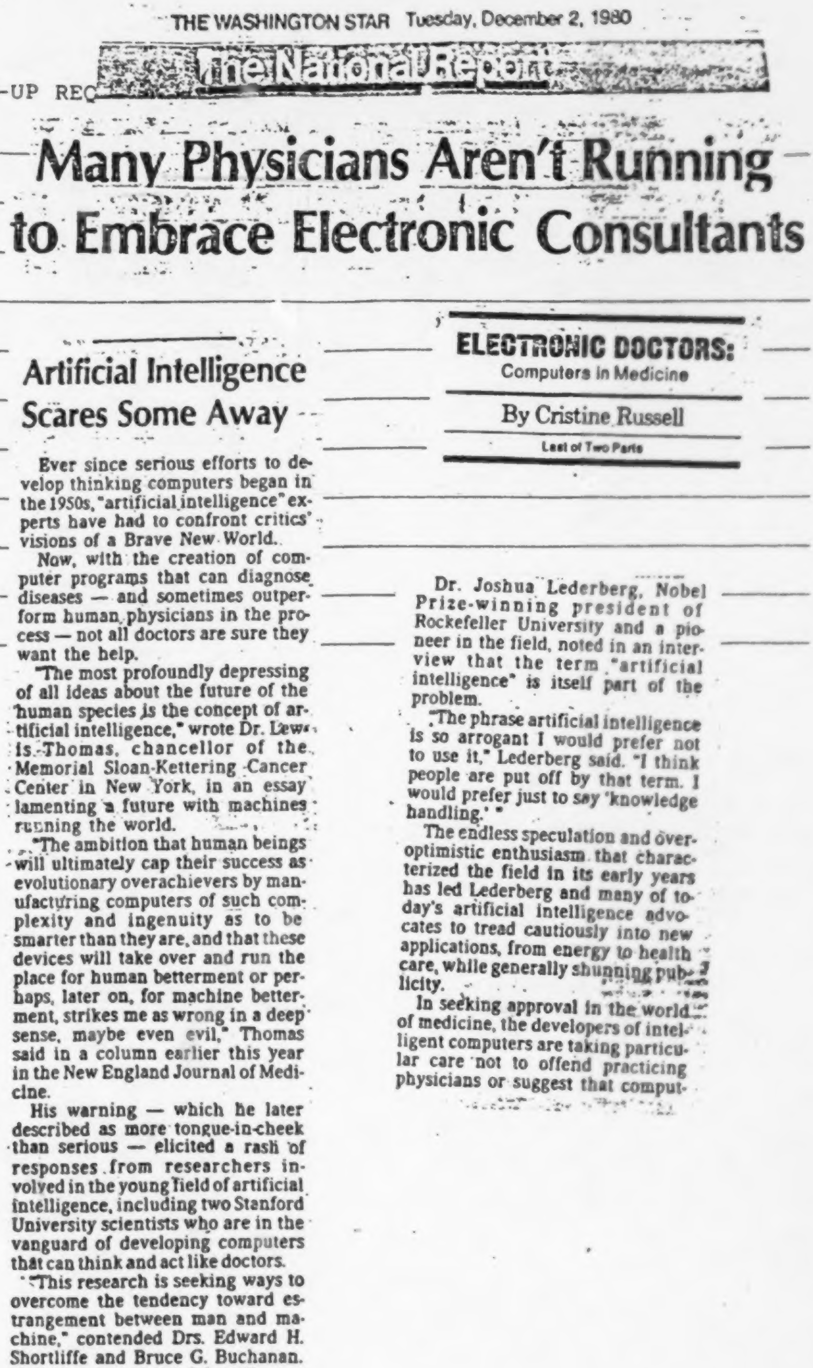

THE WASHINGTON STAR Tuesday, December 2, 1980

The National Report

Many Physicians Aren't Running to Embrace Electronic Consultants

ELECTRONIC DOCTORS:
Computers in Medicine

By Cristine Russell

Last of Two Parts

Artificial Intelligence Scares Some Away

Ever since serious efforts to develop thinking computers began in the 1950s, "artificial intelligence" experts have had to confront critics' visions of a Brave New World.

Now, with the creation of computer programs that can diagnose diseases — and sometimes outperform human physicians in the process — not all doctors are sure they want the help.

"The most profoundly depressing of all ideas about the future of the human species is the concept of artificial intelligence," wrote Dr. Lewis Thomas, chancellor of the Memorial Sloan-Kettering Cancer Center in New York, in an essay lamenting a future with machines running the world.

"The ambition that human beings will ultimately cap their success as evolutionary overachievers by manufacturing computers of such complexity and ingenuity as to be smarter than they are, and that these devices will take over and run the place for human betterment or perhaps, later on, for machine betterment, strikes me as wrong in a deep sense, maybe even evil," Thomas said in a column earlier this year in the New England Journal of Medicine.

His warning — which he later described as more tongue-in-cheek than serious — elicited a rash of responses from researchers involved in the young field of artificial intelligence, including two Stanford University scientists who are in the vanguard of developing computers that can think and act like doctors.

"This research is seeking ways to overcome the tendency toward estrangement between man and machine," contended Drs. Edward H. Shortliffe and Bruce G. Buchanan. "Workers in artificial intelligence are attempting to provide us with computer-based tools that will make doctors more effective thinkers."

Dr. Joshua Lederberg, Nobel Prize-winning president of Rockefeller University and a pioneer in the field, noted in an interview that the term "artificial intelligence" is itself part of the problem.

"The phrase artificial intelligence is so arrogant I would prefer not to use it," Lederberg said. "I think people are put off by that term. I would prefer just to say 'knowledge handling.'"

The endless speculation and over-optimistic enthusiasm that characterized the field in its early years has led Lederberg and many of today's artificial intelligence advocates to tread cautiously into new applications, from energy to health care, while generally shunning publicity.

In seeking approval in the world of medicine, the developers of intelligent computers are taking particular care not to offend practicing physicians or suggest that computers will replace human doctors. To alienate the already skeptical, and powerful, medical community, which has always been alert to potential threats to the traditional doctor-patient relationship, could place an unsurmountable roadblock in the growth of computer medicine.

"We're not trying to put doctors out of business," said Dr. William Baker Jr., a National Institutes of Health official involved in the development of biomedical computer programs. "But medical specialists are going to have to get involved with these systems."

"Medicine is going to have to change. Medical education is putting less and less emphasis on rote learning and more and more emphasis on decision-making. Computers can accumulate accurate knowledge far beyond that which any human mind can hold. People will be forced to work with them," he added.

"I cannot imagine replacing a physician with an automaton," Lederberg said. "But as a physician assistant there's a role these programs could play today." Unfortunately, he said, "the resistance is substantial within the medical profession, largely because of misunderstanding of the uses."

With many of the intelligent computer programs getting closer to application, the tiny, tightly knit community of artificial intelligence experts dealing with biomedical problems — fewer than 100 worldwide, by one estimate — is now seeking to expand its ranks, make converts and spread the word to those who eventually will use these products.

Stanford University recently sponsored a special "tutorial" session for practicing doctors. The organizers were "astounded" at the response — more than 200 doctors showed up for a two-day session that began at 8:00 a.m. on a Sunday morning.

Although few medical schools yet offer courses in this area, a select group of institutions are beginning to turn out physicians with a doctorate in computer science as well as an M.D.

"The majority of physicians wouldn't know what we're talking about. It's a whole new field," said Dr. Jack Myers, a University of Pittsburgh internist who has developed the CADUCEUS computer program, which is about to undergo field testing.

What advantages would this and other computer programs offer doctors and patients?

Myers believes that the computer diagnosis of more than 500 diseases available in his CADUCEUS program would not only save doctors time but also save money for the consumer.

"When CADUCEUS is complete and operating, it will save enough in direct patient workups — labs and X-rays — to more than pay for itself. If it works the way I believe it will, it will give indications to physicians as to what needs to be done and what's important to solve the problem."

He estimated it might cost $25 to $50 for a computer to analyze a complicated case. And while he agreed that it won't "replace specialists," he said that an expert computer doctor "might cut down on consultants." In today's increasingly specialized medical world, a patient may often be shuttled from doctor to doctor, at great expense, to get an out-of-

6

FOLLOW-UP REQUIRED:

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the ordinary health problem diagnosed and treated.

Dr. Donald A.B. Lindberg, a University of Missouri physician who has been active in the evolution of medical computers and information systems for 20 years, believes that "artificial intelligence is good medicine."

But, he said, doctors must necessarily be responsible for the hands-on treatment of patients, observing their symptoms and then deciding whether to ask a computer for help. "If doctors' egos are threatened by computers, we should console ourselves because humans are needed for the actual clinical observations. There is no way we will be bypassed."

He said specialists can never be eliminated because a "smart computer program can only work when it gets good input." But he said that specialized computer programs, like the EXPERT program he is helping develop to diagnose rheumatic diseases, may be particularly attractive when human experts are in short supply.

"If I had a disease, I would want to see an expert. But only 2 percent of people who have arthritis ever see a rheumatologist," Lindberg told doctors attending the Stanford symposium. In a six-month test of difficult case histories, EXPERT correctly diagnosed more than 90 percent of the cases presented.

But even the advocates are concerned that enthusiasm for computer medicine be tempered by realistic assessment of the limitations of artificial intelligence. Not all of medicine can be translated into computer rules, Lindberg said, and the programs themselves must have some built-in capability of deciding when not to act.

"An intelligent program must have some knowledge of its own limitations and offer no advice on some occasions. My lofty goal is for a system to be authoritative when it knows enough and humble when it doesn't."

Over the next 10 to 15 years, he said he expects computers to find their way out of the research setting and into the doctor's office. He said that prospect will be aided not only by advances in artificial intelligence research but by the technology of computers themselves.

The "microprocessor revolution" — making computers smaller and smaller — is advancing so quickly tha many expect the hardware problem of developing a desksize computer containing a complicated program to be solved.

Lindberg's more cautious colleagues cringed when asked for "crystal ball" predictions and rejected any estimate of when intelligent medical computers will become a feature of medical practice.

"That's like being asked when you are going to have the cure for cancer. I'd rather be cautious about predictions," said Stanford's Shortliffe. He recalled the early forecasts of his predecessors, which "oversold" the speed with which artificial intelligence would be applied, and said he prefers to avoid further "premature" estimates that might open the field to more criticism.

"It's likely that within 10 years there will be widespread use in clinical settings. But I don't really know exactly what impediments will get in the way," he adds. "We're on the verge of having doctors use our systems, moving research from the labs to tests in clinical settings."

Lederberg said that, in any case, the problems in bringing artificial intelligence into general practice go far beyond the researchers themselves. They will be "institutional and procedural rather than technical. Who is going to pay for it? Third-party payors (insurance companies) are not going to want added cost during the development period, even though it may pay off later."

Some have also questioned whether computers with the capability of making medical decisions might also raise additional malpractice problems. But one expert in the field said, "if they're good enough, it may become malpractice not to use them."

Nonetheless, should the promising performances of early artificial intelligence efforts prove successful, Lederberg and others believe there is an "excellent" chance that in the foreseeable future every human doctor may be backed up by a clever computer counterpart.

Diagnostic Computer Has Name Changed

The computerized medical diagnostic program developed by Drs. Jack Myers and Harry Pople at the Univeristy of Pittsburgh, featured in this series, has undergone a name change. Formerly known as INTERNIST, it is now called CADUCEUS. The change was made at the request of the American Society for Internal Medicine, whose publication is named The Internist.

WASHINGTON STAR 12/1/80

High Rate of Suicide by Doctors Prompts Them to Find Out Why

CHICAGO (AP) — An alarming rate of suicide among physicians has prompted the American Medical Association to call for a study of why doctors are killing themselves.

The AMA's house of delegates will be asked to approve the physician suicide study at an interim meeting in San Francisco in December, according to a recent report by the AMA's board of trustees. The report noted that one in 31 physician deaths is attributed to suicide.

"What we know about physician suicides is only the tip of the iceberg," said Dr. Roger J. Smith, chairman of the AMA's committee on scientific affairs and a psychiatrist at the Veterans Administration Medical Center in Portland, Ore. Smith said he thinks the number of physician suicides "may be twice as high" as statistics indicate.

Smith estimated that one in 10 doctors will face problems with alcoholism, drug abuse or mental disorder during a medical career. The AMA trustees' report said the problem may be worse among young female doctors and psychiatrists.

The AMA's suicide study would be conducted jointly with the American Psychiatric Association and consist of "psychological autopsies" of known and suspected suicides among physicians, the report said.

An earlier AMA study has indicated that 79 percent of those physicians responding said their occupation is hazardous because of stress and exposure to communicable diseases.

"Doctors, lawyers and clergymen have the most problems with drug abuse, alcoholism and suicide, but I would say doctors are at the highest risk," said Dr. George A. Mann, head of the adult chemical dependency treatment unit at St. Mary's Hospital in Minneapolis.

Mann said physicians as well as their families and patients tend to have unrealistic expectations of doctors.

Question 2 Enclosure

REPRINTED FROM:

HOSPITAL INFORMATION SYSTEMS

An International Perspective on Problems and Prospects

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HOSPITAL INFORMATION SYSTEMS: FROM THE PERSPECTIVE OF CONTINUING MEDICAL EDUCATION AND INDIVIDUAL ASSESSMENT OF PHYSICIAN PERFORMANCE

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Consideration of Hospital Information Systems (HIS) from the perspective of continuing medical education and assessment of the quality of medical care calls first for an overview of medical education itself. The field of medical education is so broad and is changing so rapidly that it may be defined in a wide variety of ways. For the purposes of this paper, we shall view medical education as an interwoven fabric wherein strands of medical knowledge are interlaced with the strands representing the skills with which the knowledge is used by the physician in the care of his patients.

In the early years of a student's medical education (beginning in the medical school years) the primary task is the acquisition of medical knowledge. The student must learn the language of medicine; the names of the macroscopic, microscopic, and ultramicroscopic parts of the body; how they function; how they react to disease; and how they relate to each other in unison or independently. The initial and continuing task of memorization is formidable, sometimes seemingly overwhelming but, nevertheless, essential. Concurrent with this task - or we should perhaps say preferably concurrent - the student learns the answers to how; the initial memorization merges with a developing understanding of the meaning of all this knowledge of medicine.

For the creation of the fabric of medical competence, the strands of knowledge must be interwoven with strands of skill in the application of the knowledge. Only then does the fabric of a professional career become a reality. To be sure, this fabric may appear - and does appear - in a wide variety of patterns variously called clinical disciplines, medical specialties, medical sub-specialties, or fields of research. But whatever the pattern, our perspective of the life-long process of medical education involves these two basic elements: (1) the initial and continuing acquisition of medical knowledge and (2) the accompanying interwoven acquisition of clinical skills which constitute the art of medical practice as the physician applies his knowledge for benefit of the health of people individually or collectively.

As we shall endeavor to demonstrate, Hospital Information Systems not only have a usefulness in making new medical knowledge directly available to the practicing physician when he needs it as he meets the problems of his patients, but also the readily retrievable computerized record of the management of the patient offers a potential for a new dimension in assessing the quality of medical care provided by the practicing physician. This latter point, which is the final point of emphasis of this paper dealing with assessment of the competence of the provider of medical care, could become an essential component in attaining the objective of quality assurance, which is viewed by many in government, in society, and in the profession itself as one of the most dominant issues before medicine today.

MEDICAL INFORMATION SYSTEMS - HOSPITAL INFORMATION SYSTEMS OPERATIONAL AND EFFECTIVE

A survey of the current medical literature reveals a large and increasing number of computerized information systems; some designated as Hospital Information Systems (HIS); others as Medical Information Systems (MIS). The list includes those that are well established and a number that are in the process of development. Some programs - relatively few - are described as large scale and comprehensive, with capacity that includes and integrates manifold functions of the hospital in its dual function as an educational institution and as a service agency. Other programs have more limited objectives as they deal with selected parts of the whole as, for example, a specialty of medicine or surgery or a particular technology or modality such as radiology or electrocardiology. The latter are spoken of as modular forms of HIS in contrast to the large-scale comprehensive systems.

At the present time, however, there does not exist a single installation of what we would consider a "Total Hospital Information System," incorporating all of the possible modules currently existing in a variety of health care institutions. The working together of appropriate modules in an integrated total system may be looked upon as an ultimate - though formidable - objective.

THE TECHNICON MEDICAL INFORMATION SYSTEM (TMIS)

Among the well established and more comprehensive programs is that which has been operational since 1972 at the El Camino Hospital, Mountain View, California. Financially supported by the Technicon Corporation, the system has been designated as the Technicon Medical Information Systems (TMIS). It is one of three different kinds of computerized systems that were selected for an "impartial analysis of medical information systems" by the U.S. Office of Technology Assessment at the request of the Office of the U.S. Senate Committee on Human Resources.[1]

In a detailed description of TMIS by Dr. Ralph J. Watson,[2] it is recognized that the El Camino Hospital has no ambulatory service, no emergency room, and no internship or residency program, so that the educational potential of the program is limited to the hospital's medical and nursing staff including 307 active physicians, 49 staff members, and 154 courtesy staff members.

A basic principle of the system is that the individual generating the data is the one to communicate the data to the computer. The hardware includes 60 computer terminals located throughout the hospital with two on most nursing units and others distributed according to need. The terminals are VMT's (video-matrix terminals) each with a television screen, keyboard, light-pen, and a high speed multiprinter for producing "hard copies" of reports. The light-pen is a key feature since it enables the user - physician or nurse - to interface with the system with only occasional need to use the keyboard. Thus, by making appropriate selections among the words or phrases presented on the TV screen, the physician communicates to the computer basic data pertaining to the patient, what is required for procedures, laboratory tests, and ordering of drugs. The physician's progress notes, most of the nursing notes, and the patient's history and physical examination are recorded manually. Thus, the patient's medical record is a composite of both computerized notes and non-computerized sections. Subsequently, the computerized record continues with data resulting from tests and procedures and the continuing condition of the patient. Radiology results are available to the physician at the terminal as soon as they are entered by the X-ray department.

This entire process of producing the patient's chart replaces the traditional written records with its hard-to-find and sometimes hard-to-read accumulation of notations and progress notes. Furthermore, it is immediately retrievable at any authorized station in the hospital for purposes of obtaining information or for making additional entries.

In the description of this program by Dr. Watson, emphasis is placed upon the feature of educational value to the physician and consequent benefit to the patient. During the process of making a diagnosis, ordering tests, or treatment, the physician can call on the computer program for medical reference information and for the latest information on available drugs, drug dosages, drug incompatibilities and allergies pertaining to the management of this individual patient. current medical or surgical abstracts may be included in the program, thus vastly extending the knowledge base of the individual physician without recourse to the library before proceeding with his care of the patient.

Dr. Watson also draws brief attention to the advantages of the system for the hospital pharmacy, the admissions office, and the business office. He concludes that "the installation of a large-scale professionally oriented computer system at El Camino Hospital has been a success in all areas of involvement." But both Dr. Watson and Dr. Jenkin, who follows Dr. Watson's paper with an editorial comment, offer words of caution: "El Camino's installation is one of the early successes among a host of failures." These failures, as Dr. Jenkin points out in his editorial, must be attributed to "their attempt to be 'total information systems'. It seems appropriate to concentrate on the most cost-beneficial applications first - a total plan does not preempt some modularity in implementation, which is to be encouraged for many obvious reasons beyond the cost question."

THE PROBLEM-ORIENTED MEDICAL INFORMATION SYSTEM (PROMIS)

A second example of a comprehensive computerized information system included in the analysis of the OTA report[1] is that which is established in the 450 bed teaching hospital at the University of Vermont. In order to understand this system, it is necessary first to be familiar with the radical restructuring of the medical record of the patient, The Problem Oriented Medical Record (POMR), advocated over many years by Dr. Lawrence L. Weed, Professor of Medicine at the University of Vermont College of Medicine.[3, 4, 5]

It is not our present purpose to deal with the intricacies of the unique manner of recording the patient's history, examination, management, and progress characterizing POMR nor the impact that Dr. Weed claims for it as "A New Paradigm' for medical education and the quality of medical care. It is, however, our purpose to point to the fact that this system has now been computerized and is cited by the OTA analysis as an example of an operational, effective medical information system. The Problem-Oriented Medical Information System has all the data that is recorded about the patient stored in the computer. Since every entry shows date, time, and the staff member who entered it, the process of medical care is documented and readily retrievable for future audit. Here, then, is another example of a Hospital Information System that is technically feasible and demonstrative of the values that may be derived from it for medical education and for augmenting the quality of medical care.

A COMPUTER STORED AMBULATORY RECORD (COSTAR)

Whereas the two systems described above, THIS and PROMIS, are derived from the medical records and the data base of hospitalized patients, a third system, also used as an example of an established system in the analysis of the OTA, is an operational computer based information system limited to care of the ambulatory patient entitled COSTAR (Computer Stored Ambulatory Record). This operational system is a product of the Laboratory of Computer Science (LSC) at the Massachusetts General Hospital, the Department of Medicine at the Harvard Medical School, and the Harvard Community Health Plan (HCHP) in Boston, Massachusetts.[6] The HCHP is a closed panel, prepaid, multispecialty medical care organization that provides comprehensive medical care, including medical, surgical and nursing services, laboratory and X-ray facilities, and emergency care. The central feature of COSTAR is the centralized, integrated data base, with all information about the patient and the patient's continuing management stored within the computer and accessible at all times through terminals in patient care areas.

In discussion of the significance of COSTAR, Dr. G. Octo Barnett, Director of the LCS, and his co-workers emphasize the importance of the system's automated monitoring and concurrent feedback in relation to quality assurance as follows:[7]

> Quality assurance combines the elements of quality assessment (i.e., identification of deficiencies in quality of medical care) and the systematic application of remedial measures to achieve improvement. The aim of a quality assurance program is to correct deficiencies in medical care by changing the behavior of physicians, other practitioners, or institutions through feedback of information about the deficiencies.
>
> There are two types of feedback in quality assurance: retrospective and concurrent. In retrospective audit, the information concerning system performance is collected and analyzed after some delay following the occurrence of the event. Such retrospective review of the patterns of medical care is being actively promulgated by the Joint Commission on Accreditation of Hospitals and has potential importance for defining the needs for continuing education of the medical staff and for identifying weaknesses in institutional procedures. In concurrent audit, the emphasis is on identifying specific deviations in the care of individual patients rather than analyzing patterns of group behavior. Concurrent quality assurance implies a guarantee of standards of medical care and depends on monitoring and timely feedback that has benefit to any individual patient exposed to a deviation from the standard.

To demonstrate the effectiveness of the concurrent audit in relation to the quality of medical care, improvement in the follow-up of throat cultures, positive for Group A beta hemolytic streptococcus, was cited as an example of the value of the system. If no appropriate treatment was recorded within four days after the positive culture, the computer generated a printed notice that was brought to the attention of the responsible provider of the medical care. The conclusion was reached that "failure to record treatment by ten days following the positive culture was drastically reduced."

THE INTERNIST PROGRAMS

We have noted above the usefulness of the integrated computerized record in aiding the physician at the time when he may need the aid in studying his patient and arriving at a diagnosis. A program that is still under development is designed to meet this specific objective within the broad field of internal medicine, hence entitled INTERNIST.

Here we are dealing with an age-old tradition in medical education. The student, whether undergraduate, graduate, or postgraduate, learns both the knowledge and the art of medicine directly from the master. We can visualize, and some of us can remember, the scene at the bedside, where, together with one or more students or junior physicians, the senior clinician listens to the story of an illness, interrupts occasionally with a pointed question, checks the physical diagnosis, assembles the evidence, studies the laboratory data, and then, apart from the patient, reviews with his students and colleagues the reasons for his conclusions. In many parts of the world, we speak of this "bedside teaching" as it was done by William Osler, and we refer to it as the Oslerian tradition.

Today, unhappily, the master clinicians are too busy with administration and research; students, too many; and time, too short. We hear plaintive cries for re-emphasis on the Oslerian tradition but with little result.

It is not surprising, therefore, that we find in the increasing application of HIS, an exploration of the potential of the computer to develop a substitute for the traditional educational dialogue between the teacher and the learner.

During the past eight years at the University of Pittsburgh, Dr. Jack D. Myers, University Professor of Medicine and master clinician, has been developing a computerized system as a resource in the diagnostic process in the broad field of internal medicine.[8,9] Working with Dr. Myers in the development and perfection of this program is Dr. Harry E. Pople, Jr., an expert in computer science. The program proceeds from the more general information about the patient to the more specific; it identifies inconsistencies and provides probabilities in relation to age, sex, and occupation of the patient. From an analysis of the diagnostic routine familiar to the expert clinician, Dr. Myers and Dr. Pople establish the following criteria for this program: observations fed into the computer must evoke the appropriate hypothesis of diseases; hypotheses must generate a set of manifestations that would be present in the patient if the diagnosis is correct; the computer must be able to rank models of disease according to their probability of being correct and must be able to decide when the weight of evidence is sufficient to permit reasonably confident judgments; the program must be able to group hypotheses into mutually exclusive sub-sets corresponding to different diagnoses in order to handle cases in which more than one disease may be present. Although, at present writing, INTERNIST covers a very large proportion of the knowledge of the diseases and their interrelationships within the field of internal medicine, it is not yet complete and will admittedly need constant revision in keeping with the rapid advances in medicine.

MODULES DESIGNED FOR SPECIFIC TARGETS

The rapid growth and proliferation of HIS during recent years has been marked by a wide variety of modules which reflect the specific interests of the individuals and institutions where they have developed. Among these is a module now operational at the Division of Cardiology at the Duke University Medical Center in Durham, North Carolina. As described by Dr. Robert A. Rosati and his co-authors, the objective of the program is to expand the ability to care for patients with ischemic heart disease.[10] At the date of their report (1975), a data bank, containing their clinical experience with more than 3,000 patients with ischemic heart disease, had been developed. All data pertaining to these patients was stored in a computer information system that enables the physician to recall the experience of patients like the new patient under his care.

The authors conclude that "We have likened these data banks to chapters in a computerized textbook of chronic disease. The computer textbook gives the physician new information in a form that is not present in printed textbooks, monographs, or journals. With a computer textbook, the physician can identify conditions in patients similar to that in his current patient and find out what happened to those patients with or without different forms of therapy."

Another module has been developed at Stanford University by Edward H. Shortliffe, where a computer is being utilized in antibiotic therapy.[11] The system is called MYCIN. Its prime purpose is to assist the physician in the selection of antimicrobial therapy for patients with severe infections.

Similar data bank retrieval approaches for decision-making and educational assists are used by Dr. Homer Warner at the Latter-Day Saints Hospital in Salt Lake City, Utah, where he uses a system named HELP which provides access to the patients seen at the hospital.[12] A specific data base on hepatitis problems and related literature data has been developed by Dr. Lionel Bernstein at the National Library of Medicine.[13] And yet another, dealing with acid base problems, was developed by Dr. Howard Bleich at Beth Israel Hospital in Boston, Massachusetts.[14]

Finally, one more example of a modular program has been selected for the purpose of this paper, not only because of its special interest, but also because of the location of its origin. A report in the South African Medical Journal by Doctors A. J. Brink, C. De W. Vivier, and J. D. N. Van Wyk describes a system for computerized analysis, interpretation, storage, and retrieval of electrocardiograms.[15] The authors conclude that "such systems are at a stage where they can be feasibly introduced and should be of advantage in freeing the physician from routine measuring and screening electrocardiograms, thus saving many hours of professional and academic time...Furthermore, such systems can contribute greatly as an educational tool and increase the general knowledge of electrocardiography."

COMPUTERIZED INFORMATION SYSTEMS:
A POTENTIAL FOR INDIVIDUAL ASSESSMENT OF PHYSICIAN PERFORMANCE?

We have reviewed briefly some of the contributions being made by hospital information systems and medical information systems both from the experience of effectively established large-scale, comprehensive systems and from the experience of modular programs designed for closely defined specific objectives. We have seen some of the educational usefulness of these systems in bringing critical knowledge and a clinical data base directly and immediately to the physician when he is formulating the diagnosis and plan of management for the patient. Here, then, we come to the point of primary importance emphasized at the beginning of our consideration of computerized information systems from the perspective of medical education and assessment of the quality of medical care. Does this new technology have a potential - a potential that has not yet been developed - to evaluate and assess the actual, real-life performance of the individual physician in the daily and continuing practice of medicine?

If we return to our initial perspective of medical education as a career-long process in which the strands of advancing medical knowledge are continuously being interwoven with the clinical skills by which medical knowledge is applied competently to the patient, our question about the evaluation of the competence of the physician becomes twofold: first, that of assessing medical knowledge and, secondly, that of assessing the less definitive skills of performance.

The answer to the first part of this question has become a part of the on-going history of medicine. Examinations of the cognitive medical knowledge of the physician may vary - and have varied - in form and substance from time to time and from one part of the world to another. But the fact of the examination of the knowledge of medicine has long been well established. In the 13th century in Southern Italy in the empire of Frederick II, an important step was taken to protect society against the ignorance of doctors.[16] Definite standards were set for medical education requiring three years of philosophy, five years of medicine, and one practical year, whereupon the candidate was examined by the Masters in Salerno in the presence of a state commissioner. No doctor was to practice without a license. This step, which today might be viewed as directed toward control of the quality of medical care, has a very familiar ring in the current examination systems that lead to an official license.

In the United States and to a large extent around the world, oral examinations and examinations in essay form have given way to the more objective multiple-choice questions.[17] We have confidence in our ability to evaluate the acquisition of medical knowledge and the ability of the physician to keep in step with the advances of medical knowledge. Furthermore, we can, and we do, devise tests to determine that the physician not only has knowledge, but that he also knows how to apply the knowledge to the patient. But the question still remains, how can we be sure that the physician not only knows what to do, but does it, and does it skillfully?

The ability to answer this latter question confidently is a major challenge to agencies and institutions responsible for the licensure of the physician for the practice of medicine, for certification that the physician is qualified for recognition as a specialist in a chosen field, and now, increasingly in the United States, that the physician maintains this qualification throughout his professional career. This challenge has, to an increasing degree, stimulated research studies designed to yield new methodology for valid and reliable assessments of the performance of physicians - assessments that reach beyond assessment of medical knowledge alone.

One of the avenues of research designed to evaluate individual physician performance is the Chart Audit System. Charts of patients, whether confined to the hospital, in the hospital's ambulatory service, or in the doctor's office are used as a basis for evaluation of the actual performance of the physician.

Expert committees have prepared lists of data to be collected and tasks to be accomplished which the committees judged as essential for the proper evaluation and management of patients with specified clinical problems. Determinations were then made of the extent to which an individual physician had complied with the listed criteria and a score derived.[18]

The above described approach has certain problems. These include the selection of the charts for audit; the retrieval of charts by problem or diagnosis; the reliability of the record auditor; the development of scoring systems that are reflective of the physician's performance; determining the number of records by conditions that need to be audited to provide a stable measure; the relationship of process criteria to patient outcome; and finally, and most important, the validity of the medical record as an indicator of what the physician did or did not do in actual management of the patient.

At present, one comprehensive study that is attempting to deal with these problems is being directed by Dr. Paul Sanazaro for the American Hospital Association and the American Society of Internal Medicine.[19] This study, entitled "Private Initiative in Quality Assurance (PIQuA)," explores the feasibility of establishing from the patients' records an on-going program for periodic, formal recognition of the competence of practicing internists, involving both medical and hospital services.

We could pursue at length many more examples of the use of the record as the basis for evaluating the performance of the physician. Also, we recognize that this approach toward the assessment of performance and hence the competence of the individual physician is the subject of intensive research as one component of the current wide-spread emphasis on the control and improvement of the quality of medical care received by the patient. As this research progresses, it appears inevitable that sharper lines will be drawn on audit criteria and the contribution that they may make to definition of the adequacy of physician performance. But even the more sophisticated techniques of chart audit, as they may continue to gain acceptance as a result of current and continuing research, rely upon the written record of hospitalized or office patients for evaluation of the performance of the physician and hence are still at least one step removed from a real-life assessment.

We turn then to computerized information systems as a new modality that has a promising potential yet to be developed for evaluation of physician performance and quality assessment. Large-scale, comprehensive programs or more restricted forms have the capability of providing data for evaluation of certain aspects of the actual performance of the practicing physician. For example, as noted above in our description of COSTAR, it becomes possible to determine instantly how often the physicians used certain treatment procedures such as antibiotics, diuretics, or tranquilizers. Just as readily, the specific diagnoses that were made which resulted in the decision to use a specific agent could be displayed.

With computer capability now available and making it possible to have a terminal at the hospital nurse's station or even in the doctor's own office, the complete record of the patient can immediately be retrieved to bring to the finger-tips of the physicians the patient's history, physical examination, laboratory data, initial diagnosis, clinical course, final diagnosis, and continued follow-up during any part of the treatment process. The actual day-to-day performance of the physician is available for review and study of the completeness of the history and physical examination, the physician's judgment in treatment, and the quality of continuing management of the patient.

To be sure, there are difficult questions to be met as to what constitutes adequate or inadequate performance and how medical information systems can be used to provide reliable and valid data that are reflective of this performance. In dealing with the issue of what constitutes adequate and inadequate performance, the medical profession has a long record in establishing criteria and in passing judgment on the knowledge and competence of its students and also among its peers. We develop criteria for the adequacy of the physician's medical knowledge for general or for specialty practice. We make judgments about clinical competence derived from simulated problems in written examinations and oral examinations, or real problems at the bedside and, within the limits of practical feasibility, with the use of simulated models. Is it beyond our capability to develop reliable and valid criteria to evaluate the performance of the physician taken from an accurate computer-generated record of the physician's performance in a real-life situation? We do not think so. Rather, we see a new modality available and waiting for skillful development of valid and reliable assessments of the competence and demonstrable skill of physicians retrieved from concurrent audit and the identification of unacceptable deviations in the care of individual patients.

In dealing with the issue of developing reliable and valid data in making judgments about the adequacy of physician performance utilizing medical information systems, we realize that a great deal of research needs to be done. We close, therefore, with this challenge to those with an interest in developing the potential of the computer as a component of both medical education and the assessment of the quality of the medical care for the people of our countries.

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DISCUSSION V - MEDICAL

I am going to present very briefly the sum of our discussions this morning. We chose just a few of the many points which had emerged from the papers this morning and discussed them at some length.

Firstly, we considered the possibilities afforded by the video disc, or the laser optical reading facility, which now seems to be available. This idea was presented by Dr. Hartgerink today and was originally presented by Dr. Lindberg in his keynote address. We felt that this was very interesting and could certainly have significant medical benefits, as it appears to afford the possibility, for the first time, of being able to coalesce video or image-type information together with digital information. We also discussed, in some detail, the possibilities afforded by Dr. Hubbard's view of the future of continuing medical education and medical audit. The fact that information systems could, almost as a byproduct, provide for review of the physician's competence and his performance in the hospital setting. There were some doubts as to where this might lead us. We might possibly have a tiger by the tail unless it is controlled in a way which retains the right within the profession to manage its own affairs rather than arrogate this right to other people. We also discussed artificial intelligence and the possibilities that this might afford, particularly in the medical aspect where the system might not only indicate what sort of decision it had made but specify exactly why it had been made. This would certainly afford help to the physician and the health care professional in their care of the patient and also in their education. We then entered into a discussion of where hospital information systems and medical information systems would go from here. We discussed how all the major development that was necessary could be financed and what directions development might take. Countries such as Japan which have set up co-operation between the Ministries of Commerce, Industry and Health, together with universities as a co-operative venture might take the lead in the development of Hospitals Information Systems. Possibly, in other countries, there could also be some sort of co-operation between industry and universities or research institutions in further developing Hospital Information and Health Care Information Systems.

DISCUSSION V - MANAGEMENT

Our discussion recognized the importance of timely forecasting for the success of change management. Because the realization of change is such a time-consuming activity - requiring 10 to 15 years in cases of radical change, adequate time-forecasting is essential to the successful implementation of change.

Forecasting is complicated by the factor of uncertainty, but this factor can be reduced by prognoses. Prognoses should cover the following:

. technological changes,

. social changes (economic, political, social, and physical)

. changes in the availability of resources (manpower, education, facilities, financial support)

Because managers in the health field have to deal with a wide range of problems, they cannot be expected to adequately understand technological changes. Therefore, advisory bodies or research centers, such as those suggested by dr Hirel, should be created to serve as resources for managers in this field.

If managers are to execute their responsibilities in a systematic manner, planning must be recognized by them as an essential tool. Planning starts with policy development. In the context of developing the HIS, the group recognized that policy development within the hospital should ideally be developed within the overall policy development of the health care system. Any considerable policy change should be worked out in strategic (10 to 15 year) plans which, in turn, will serve as the basis for shorter term, "rolling" operational plans. These operational plans should then be broken out in terms of project plans which should be specified in annual budgets and annually revised.

Health Care planning at the macro-, meso-, and micro-level should be coordinated to maximize its benefits.

. Macro-level planning concerns itself with the Health Care System as a whole, whereas meso-level planning is concerned with the hospital alone. For maximum effect, hospital or meso-level planning, should recognize external factors (as listed in the prognoses) as well as internal factors peculiar to the individual hospital.

. Another significant application of planning exists at the micro-level: patient (patient flow)-scheduling; investigation (lab. tests, X-rays, etc.)-scheduling; and patient care or treatment planning.

The group noted the development gap which exists between health services (or hospital) planning, on the one hand, and information systems planning on the other. Health services planning is rarely - if ever - implemented in a comprehensive manner, whereas information planning receives much attention and is applied extensively.

In the context of the discussion of The Future, these main problems in regard to management were identified:

. lack of management expentise and understanding of management processes within the hospital organization.

. lack of authority on the part of the manager responsible for developing and implementing the Hospital Information System.

. lack of adequate resources.

It was concluded that the manager responsible for HIS development should be a member of the top-management team with executive authority. This person should possess personal qualities - (initiative, motivation and drive) which will enable him to create a collective will to change. This concept should be assimilated at all levels in the institution, so that the responsibility for every aspect of the information system and the associated reorganization would be assumed by the manager (or physician) in charge of each service unit.

Finally, the discussion turned to the spcial problems of the developing countries where the group felt problem-oriented solution must be sought. In developing countries, environmental variables will be less standardized than in technologically advanced societies, and, therefore, each of these developing countries should analize their own needs and problems and develop their own solutions because it is unlikely that ready-made, imported solutions will be found. Assistance from the industrialized nations would be of great value in this process.

Recommendations

1. Long range planning should include policy development; strategic, operational and project planning; and budgeting.

2. Taking due account of forecasts of external circumstances and internal factors, i.e. given the opportunities and constraints, the objectives of Hospital Information Systems should be established, the configuration of the system designed and the resources allocated.

3. To facilitate decision-making, advisory bodies or research centers should be created for research, development and service.

4. The needs of developing countries should be regarded as a special problem. The developing nations should be encouraged and helped to investigate their own needs by means of a problem-orientated approach and to find their own solutions with the assistance of the industrialized nations.

DISCUSSION V - FINANCIAL AND ECONOMIC

Hospital Information Systems provide an excellent tool for the use of all members of the health-care team. The focus of this team effort should be the patient.

Some of the areas that will or could impact on the financial and economic picture in the future are the following:

1. Reduction of hardware and software costs in central site and total costs could increase overall.

2. Sharing of software development costs.

3. Standardization and compatibility of hardware and software

The group gazed into the cloudy crystal and made some other comments:

1. A computer terminal is a forseeable addition to the office of the general practitioner. It can be the "window" to a diagnostic data base to assist the physician in his daily activities and be used for some form of continuing medical education.

2. A computer terminal for each hospital bed that will serve the patient for education and enjoyment, and serve the health care team as an information device.

DISCUSSION V - EDUCATION AND RESEARCH

Background

Computers in various sizes and types are becoming an important part of the environment within the hospital. They increasingly support many functions, and hospitals will depend heavily on computer systems in a decade.

Problem

The future development of HIS may go in various directions. It is difficult to predict to what extent the medical profession will accept computerized HIS and which applications will be the most useful ones for the patients, the physicians and the hospitals. As the technology changes and the applications get more advanced, it is difficult today to anticipate the best examples for future teaching and to incorporate them into the education of medical students and medical doctors beforehand.

Recommendation

Basic facts on HIS as a tool should be incorporated in the training of medical students and of medical doctors working in the hospital

There should be more on the job training with existing systems. This will enable physicians to follow closely the technology development and the real situation in the hospital environment regarding computer applications.

It is recommended that possibilities to assist the patient's education be explored in the future design of HIS.

We believe that the early introduction of modern computer methods will lead to increased familiarity and facility which will later encourage the physician's use of HIS

Question 2 Enclosure

HOSPITAL INFORMATION SYSTEMS AS WE ENTER THE DECADE OF THE 80'S

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ABSTRACT

This paper will address the findings of a recent survey conducted by Marion J. Ball, Ed.D. and Stanley E. Jacobs, Ph.D.

A brief history of computers in the medical environment will be covered. Basic terms and levels of hospital information systems sophistication will be addressed. The findings of the survey will be graphically illustrated and a cautious prediction will be made as to what the hospital population can expect in the next decade of computer use in their institutions.

In the June 16, 1980 issue of Hospitals, the authors traced the development of hospital information systems, provided a working definition of a Level 1, Second Generation Hospital Information System, and predicted the rapid prolification of such systems.[1]

The classical First Generation Level 1 HIS of the 1960's encompassed a basic set of applications for in-patients. These were:

1. An ADT application with bed status and census reporting.
2. An order/requisition entry, communication, and charge collection application.
3. An inquiry application for today's charges for demand bill purposes.

Second Generation, Level 1 systems now include these same applications, but in addition all vendors offer a variety of additional applications which greatly enhance the usefulness of the HIS to the hospital and its high volume departments. A listing of "enhancement applications" is contained in Table 1 together with indication frequency that each application is offered by a sample of 8 vendors.

The information provided by Table 1 shows that today's Second Generation, Level 1 Systems go way beyond the three applications of First Generation Level 1 HIS. For every one of the 36 applications listed in Table 1 over half of the vendors indicated that they now offered or planned to offer the application. Careful study of the application list will reveal that certain applications require a computerized patient record to be maintained throughout the patient stay. For instance, a patient medication profile requires that medication data be retained for the entire stay of the patient.

What has happened, of course, is that just as the Level 2 systems[2] have grown over time in the number of functions they accomplish, so have the Second Generation Level 1 systems grown. The survey showed all vendors to be offering dynamic, continually growing systems.

The scope of a vendor's Level 1 system will vary from hospital to hospital. Some hospitals may contract for most or all of a vendor's enhancement applications, while others may be satisfied with little more than a classical Level 1 HIS. Some vendors will even sell an Admitting-Discharge-Transfer system only, perhaps hoping that the hospital which purchases the ADT system will upgrade to a full Level 1 system in the future.

A word of caution is in order. Within an application the amount of support it provides will differ from vendor to vendor. When choosing between vendors, a hospital must look into each application in depth to decide upon its merits.

The findings from a May 1979 survey of vendors were updated in April 1980 to provide current information in Tables 2-5. These findings are summarized as follows:

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[1] Ball, M.J. and S.E. Jacobs, "Information Systems: The Status of Level 1," Hospitals, June 16, 1980, pp. 179-186. (Most of the information provided herein is taken directly from this article.)

[2] A Level 2 System is one that has been designed from the start to capture and maintain on-line the entire patient record. As such the computer can prepare medication schedules, the data bank may be queried for patient medication, profiles, etc.

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Table 2. The fact that 18 vendors now offer Level 1 HIS is testimony to the adaptability of American industry. In addition, the survey found 5 more firms which will probably soon enter the marketplace.

Collectively more than 500 Second Generation Level 1 Systems have been sold as of Spring, 1980.

Hospitals of all sizes have installed Level 1 HIS's. This is contrary to earlier beliefs that a hospital must have over 250 beds to justify such a system.

The Cathode Ray Tube (CRT) is by far the input device preferred by the industry.

IBM is listed in Table 2 because it does provide software and hardware for a Level 1 HIS. However, the support to get a hospital up and running provided by IBM is somewhat less than by the other vendors. It is up to the hospital to have a relatively sophisticated data processing department to implement the IBM Level 1 system. In other words, turnkey support is not provided. IBM also offers Level 2 HIS software. Nevertheless, the IBM approach is an option that should be considered by hospitals which have in-house, well qualified data processing staffs. The Burroughs Level 1 and 2 offerings are likewise much less a turnkey proposition than are those of the other vendors.

Table 3. Eight of the vendors also offer shared business and financial systems. (Most of the other vendors now offer in-house business and financial systems.)

Table 4. Six of the vendors also offer Level 2 HIS's first and then, perhaps spurred by the success of HBO, brought a Level 1 system to the marketplace.

Table 5. The magnitude of funds expended by vendors for Level 1 and/or Level 2 HIS development, and the funding they have committed for research and development for the next year or two are shown in Table 5. This certainly suggests that these companies are deeply committed to the HIS marketplace. Because of their R&D investments, they can now bring HIS to hospitals at much lesser cost to the hospital than the funds required for a self developed HIS. At the same time they can save the hospital a lot of development time and implementation trauma.

In these times when hospital administrators must be extremely cost conscious, can they justify the installation of any level of HIS? In his remarks to a congressional committee, Hodge advised that "Level 2 and 3 systems are or could be cost effective. Level 1 systems are adding to hospital costs."[3] If the latter statement were true, then the sales of Level 1 systems would have come to a screeching halt. But fortunately for the industry and for hospitals, the facts deny Hodge's statement.

For instance, this article documents the fact that over 500 Second Generation Level 1 HIS's have been sold. Most of these had to be cost justified for Health Systems Agency approval. Apparently, hospitals with vendor assistance have been quite successful in proving to HSA's that Level 1 systems are cost effective.

It is beyond the scope of this article to go into the factors by which one justifies a Level 1 HIS. A brief statement on costs must be addressed, however. Let it merely be said that some of the factors may be categorized as "revenue increasing factors," some as "cost reduction factors" and some as "cost avoidance factors." They are precisely the same factors that are used to cost justify all levels of hospital information systems. For many factors the cost benefits from a Level 1 system will be exactly the same as the benefits from the Level 2.

Summing up the above, cost justification is not a problem. The cost benefits to be derived should stimulate sales in the cost conscious posture of hospitals today.

Another stimulus to continued healthy sales of Level 1 systems is the increasing awareness on the part of the hospital administrators that these systems are no longer just "charge collection and message switching systems." They have become a viable alternative to the much more costly Level 2 systems. The Level 2 systems cost range for hardware and software is $4.00 to $7.50 per patient day; for Level 1 systems the cost range is $1.50 to $2.75 per patient day. Some hospitals are simply not ready for extremely sophisticated systems, and some administrators are not yet ready to risk the Level 2 implementation process.

Prospects for continued healthy sales of Level 1 HIS are predicted for the next five years. By 1985 at least 1500 short-term general hospitals will have installed the Level 1 systems, and most of these will have a full spectrum of enhancement applications.

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[3] Remarks by Melville H. Hodge, Computers in Health Care. Hearings before the subcommittee on domestic and international scientific planning, analysis and cooperation of the Committee on Science and Technology. U.S. House of Representatives, 95th Congress, Second Office, Washington, D.C. (35-763-0).

The Level 1 vendors will continue to expand upon the applications they offer. Some will enter the Level 2 HIS marketplace in addition to those that already offer both Level 1 and Level 2. They will be forced to do so to retain their client base as hospitals become desirous in the future of upgrading from Level 1 to Level 2. They will also modify their systems so that they may provide direct usage by physicians, nurses and other professionals.

TABLE I

Enhancement Applications (8 Vendors) 197[illegible] Data

Department/Application	Number of Vendors	
	Now Offer	Plan to Offer
NURSING:		
Order Set Entry	5	1
Auto-Kardex (Charting)	3	2
Patient Care Level Tracking	3	2
Staffing Requirements	5	2
Nursing Notes	5	0
Care Plan	1	6
Medication Schedules	6	2
Medication Monitoring	3	2
PHARMACY:		
Patient Medical Profile	7	1
Drug Precaution/Interaction	2	4
Unit Dose Care Replenishment	5	2
Pharmacy Inventory	3	4
LAB:		
Specimen Collection Lists	6	1
Specimen Collection Labels	8	0
Results Reporting[1]	7	0
Cumulative Results	6	1
Interface to Lab Computer	6	1
RADIOLOGY:		
Scheduling	4	2
Report Normals Only	3	3
Report All Results	2	5
Radiology Index	4	2
MEDICAL RECORDS:		
Medical Record Index	5	2
Medical Record Abstract	5	2
Chart Loc. & Delinquency Tr.	3	3
ER/OUTPATIENT:		
Registration	8	0
Order Entry	8	0
Demand Billing	7	0
Patient Scheduling	6	2
MISCELLANEOUS:		
Pre-Admitting	8	0
Computer Assigned Patient I.D.	8	0
Time Clocking	5	0
Surgery Scheduling	2	3
Diet List Preparation	7	1
Utilization Review	7	0
Cash Receipts Entry	6	0
Doctors' Registry	6	1

[1] Some report Stats only

*The Table is based upon the responses of 8 vendors to a questionnaire listing the enhancement applications and asking whether the vendor now offered or planned to offer the application. The 8 vendors are:

BRD	Burroughs
DMS	DATX
MCAUTO	Pentamation
NCR	HBC

In addition to the 36 applications listed, collectively the vendors reported 24 more applications on a "write-in" basis. All of these were unique to the vendor that reported them.

TABLE 2

PRESENT VENDORS OF LEVEL 1 HIS

VENDOR	NO. INSTALLED OR IN PROCESS - APRIL 1980	NO. OF BEDS LEAST	NO. OF BEDS MOST	ORDER ENTRY TERMINAL
HBO & Company (HBO)	237	100	629	CRT[1]
Shared Medical Systems Corporation (SMS)	100	154	1,725	CRT
McDonnell Douglas Automation Co. (MCAUTO)	53	103	650	CRT
IBM Corporation (IBM)[3]	50 (est)			CRT
NCR Corporation (NCR)	25	284	641	BCWR or OCR
Burroughs Corporation[3]	20	191	737	CRT
DATX Corporation (DATX)	10	176	534	CARD READER
Pentamation Enterprises	9	280	800	CRT&OCR
Tymshare Medical Systems	5	80	436	CRT
Compucare, Inc.	4	250	440	CRT
Space Age Computer Systems, Inc.	4	349	845	CRT
Hospital Data Center of Virginia (HDC)	4	256	800	BCWR[2]
Spectra Medical Systems, Inc.	2	140	600	CRT
Technicon Medical Information Systems Corporation	3	446	719	CRT
Interpretive Data Systems, Inc. (IDS)	1	250	250	CRT
National Data Communications, Inc. (NADACOM)				CRT
Genitron, Inc.				BCWR
Informational Resource Electronics Corp. (IREC)				CRT (Intelligent)

Notes: 1 CRT = Cathode Ray Tube
BCWR = Bar Code Wand Reader
OCR = Optical Character Reader

2 HDC also utilized CRT's for inquiry purposes.

TABLE 3

VENDORS OF SHARED BUSINESS AND FINANCIAL SYSTEMS WHICH OFFER LEVEL 1 HIS

	1979 Data	1980 Data
VENDOR	NO. OF HOSPITALS IN SHARED SYSTEM	NO. OF LEVEL 1 HIS INSTALLATIONS
MCAUTO	561	53
SMS	490	100
Tymshare	150	[illegible]
Technicon	45	3
Pentamation	31	9
Space Age	26	4
HDC	24	4
HBO (IFAS)[1]	14	237

[1] HBO introduced a new real-time, terminal/network based financial based financial system in 1979. Their new IFAS System directly interfaces in-house to HBO's Hospital Information System (MEDPRO System).

TABLE 4

VENDORS OF LEVEL 1 HIS WHICH ALSO OFFER LEVEL 2 HIS

VENDOR	NO. OF HOSPITALS WITH LEVEL 2 HIS	NO. OF HOSPITALS WITH LEVEL 1 HIS
Spectra	18	2
Technicon	17	3
NDC (NADACOM)	10	0
Burroughs	8	20
MCAUTO	6	53
IREC[1]	4	0
IBM	Not available from IBM (estimate 50)	50 est.

[1] IREC is a relatively new vendor of HIS. Its development site was The Sisters of St. Mary Hospital Group, St. Louis. Its system is modular, and IREC claims that its complete system is a genuine Level 2 HIS. This system together with facilities management therefore is also being marketed by Electronic Data Systems, Dallas, Texas.

TABLE 5

VENDOR RESEARCH & DEMONSTRATION BUDGETS FOR HOSPITAL INFORMATION SYSTEMS
(SURVEY: M.J. BALL, 1980)*

FIRM	R & D $ INVESTED TO DATE	R & D $ TO BE INVESTED, NEXT 2 YRS
Compucare (HIS)	3,500,000	2,000,000
Datacare (PCIS)	4,000,000	1,000,000 (vary by client needs)
HBO and Company	6,000,000 (approx.)	6,000,000 (approx.)
Hospital Data Center of Virginia (HDC)	Not available	250,000
Interpretive Data Systems (IDS)	1,000,000 (approx.)	300,000
McDonnell-Douglas Automation Co.	20,000,000	4,000,000 plus
Meditech	300,000/yr. since 1969(3,300,000)	600,000
Madacom	15,000,000 on full line of patient data systems	will continue to make a significant investment in new development
NCR Corporation	6,000,000	3,000,000
Shared Medical Systems	6,200,000 during 1979	no specific data, but in keeping with past efforts
Spectra (Medicus)	25,000,000	"proprietary information"
Technicon Medical Information Systems	24,000,000 (incl. Lockheed)	4,000,000
Tymshare Medical Systems	"well over the million dollar mark"	not available
Burroughs	"does not report R&D expenditure specifically for the health care industry	"does not report R&D expenditure specifically for the health care industry"
IBM (PCS)	"not available for public disclosure"	"not available for public disclosure"

*The data listed are intended to convey the scope of the aggregate funds currently spent on development activities. This data in no way should be used to compare individual vendors to each other since each of the vendors budgeting and reporting conventions differ. The main point is that HIS development is not a minor expense.

lab computers: will performance

by Marion J. Ball, EdD and Samuel Raymond

CLINICAL LABORATORIES are still searching for effective cost efficient computer system solutions. In recent months these concerns have been more vocal, and special-interest groups are now proposing policies and taking actions intended to cure the deficiencies of existing systems. Clinical pathologists are being encouraged to take a more and more active part in these efforts.[1]

In surveying this field we agree with most clinical laboratory professionals that their clinical laboratories need data processing. The increased workload imposed by laboratory automation both in the laboratory and on our clinical colleagues makes computerization of laboratory data imperative. It is our responsibility, as the professional staff directly concerned with this process, to provide the best possible alternative solutions to the computerization of our nation's clinical laboratories. This article will review the performance of commerically available systems and present the authors' concerns for future development.

Historic development

From the early days of computer development, the clinical laboratory has been a prime focus of efforts to introduce computers into the practice of medicine.[2] Laboratory medicine is closely interwoven with quantification; hence, computers have been found to be applicable to clinical laboratory practice. This reasoning has led to the development of 14 significant commercially available systems in the last 12 years, plus an indeterminate number of other systems that have never extended beyond their originating sites in academic laboratories. To most clinical pathologists, only the commercially available systems are of practical significance, because of transportability. We therefore emphasize commercial systems in this discussion.

Exhibit 1 lists most of the significant computer systems that have been offered commercially in the past 12 years.[3] In 1968 there were approximately four systems available. Five years later this number had increased to 14, but by 1979 the number had dropped back to about five viable vendor systems. Only a couple of the original systems have survived for 12 years. Today's systems are, however, decidedly different from their original systems because hardware and software design is continually improved. In the last five years, several new companies have offered laboratory systems; it is doubtful whether they will remain in the marketplace.

replace promise?

Even more significant is the economic history of these systems. It seems that few of the companies have been able to meet their projected business objectives and therefore many have not survived. It is only fair to say here, however, that a few have survived over the past 15 years, and they are easily identified. This has to be concluded since most of the vendors on the list either abandoned their systems entirely or changed ownership in circumstances that indicated approaching financial failure.

Within the past two years, for example, Honeywell Systems, Inc. quietly abandoned its clinical laboratory system; DNA, a well-known vendor of a highly developed laboratory system,[4] ceased its operations as a subsidary of Avnet,[5] as did Laboratory Computer Inc. (LCI) with Brunswick. Technicon has also recently announced major changes in its clinical laboratory approach to computerization.

These are unquestionably legitimate business decisions based on perceived economic realities. They are important to the laboratory because of their implications for vendor support. No laboratory wants to be saddled with a system which it cannot maintain for itself and for which vendor service is not available or will not be available in the future.

Review of the current computerized laboratory computer system scene

Very few of the hospital laboratories of this country, compared to the number of hospitals in the United States, presently have computer systems operating. The total for all the commercial systems

Very few of the hospital laboratories in this country, compared to the number of hospitals in the United States, presently have computer systems operating.

listed in Exhibit 1 is in the neighborhood of 321 (less than 5 percent of all laboratories in United States hospitals). Granted there are many political and financial reasons for this, but that does not explain the proliferation of CAT scanners.

Any responsible director of a clinical laboratory will look at the overall performance of laboratory computer systems in other laboratories before committing a large share of his/her laboratory activity to the computer. If he/she has substantial doubt about its cost effectiveness, and, far more important, its medical effectiveness, he/she will refrain from the venture. This certainly is one of the reasons why there has not been greater acceptance of computerization in the laboratory.

The wise clinical laboratory director looking at existing computerized clinical systems will judge for himself/herself whether a given system is a success or a failure. He/she must ask the appropriate questions about the outcome of the process of computing, instead of merely looking at the process itself.

The answers to the following questions can provide the information necessary to evaluate a system. Note that these questions do not involve the technology of computers or the fundamentals of systems design, an area on which far too great an emphasis has been placed in the past. The questions, in fact, address the topics that are of greatest importance to the pathologist. These questions place the decision squarely in the area of his/her expertise where indeed it should be. The questions he/she most likely would ask or consider are:

- Is the physician's work easier because of the computer system?
- Is test ordering simpler?
- Is specimen pickup more reliable?
- Are reports more readable?
- Does the physician call the laboratory every day for results?
- Are specimens or reports ever lost?
- Are the chart records neat and orderly?
- Has the laboratory increased or decreased?
- Can the laboratory turn out the work when the computer is down?
- Is there follow-up of errors?
- Does the pathologist see the problem reports?
- Are there too many phone calls or stats?
- Is there a saving in cost?

Where are the basic problems?

Technology. At present, most of the commercial systems listed in Exhibit 1 rely to a great extent on one general type of computer technology: the time-shared operation with interactive terminals featuring on-line data acquisition, real-time processing and user input. There is no doubt that this is "space age" computer technology that helped us put a man on the moon. It is glamorous, fast and quite expensive. One of the major questions we laboratory specialists must ask ourselves is whether we are using the appropriate tools for *our* needs, which might not be the same as NASA's.

Laboratory needs. Does the laboratory need all that technology in practice? It is time to rethink the actual laboratory process. Laboratory work is essentially batch work. Most present computer laboratory systems include on-line systems approaches which might or might not address the need of the laboratory. It has been shown that 85 percent of the physician's use of the laboratory involves results needed according to an appropriate fixed schedule. If the physician could be assured of these services where and when he/she needs them, he/she could care less whether a computer is used. Often, therefore, we look to the computer when in fact we should be looking toward systems solutions. The principal question one might ask about current interactive system is whether the design of the system matches the environment in which it is to be used. No one should suppose that any given commercial system is a technical failure: the computer equipment performs as specified by the vendor and the programs have been tested thousands of times. In the hands of experts all works well. But when the system is operated by several hundred doctors, nurses, ward secretaries, technologists and clerks in an ordinary hospital, it is no surprise at all that the system that worked at the factory under "ideal" conditions doesn't work.

Cost. The final basic problem is cost. The cost of a laboratory system has three components: direct cost, hidden costs and benefits to cover costs. A laboratory director's prime objective in selecting a system should be to have it pay for itself completely in no more than two or three years. To meet that objective, it is essential that the system reduce personnel needed in the laboratory and in nursing.

There are two contrasting views of cost effectiveness in clinical laboratory computers. The most widely accepted view considers the computer cost-effective when it fully automates the internal operations of the laboratory. This means that the system controls the analyzers; records data; computes standard curves; calculates results and makes them instantly available through on-line terminals, and is able to recall previous reports by means of the same terminals. The primary design objective reflected in this view is to make the system as rapid and as responsive as the technology will allow.

The principal question one might ask about current interactive systems is whether the design of the system matches the environment in which it is to be used.

Exhibit 1**

VENDOR	SYSTEM	COMPUTER	INTRODUCED	USERS
*AMS (Advanced Medical Systems)	Multilab	PDP11/45	1974	* 4
BSL (Berkeley Scientific Laboratories)	Clinidata 200/400	PDP8	1968	50
	Clinidata 700	Tempo	1973	10
	Clinidata 710	Cal Data PDP1135/40	1975	10 installed 8 back log
CHC (Community Health Computing)	CHC	Modcomp	1974	12 installed 5 back log
DEC (Digital Equipment Corp.)	Clinlab 12	PDP12	1969	48
DNA (Diversified Numeric Applications)	Uni-Lab	DNA/Med 16	1968	35
Genetron	Labtron	GA 16	1975	2
Honeywell	CLMMS	H/716	1971	25 with VA
I.B.M.*	CLDAS	1800	1966	3
Infomed	LIS	Datapoint	1976	1
Infotronics	CL II	PDP8	1965	?
LCI* (Laboratory Computing Inc.)	Labcom	PDP12/PDP11	1970	40 (18 LCI) (22 DEC)
Meditech (Medical Information Technology)	Medilab	PDP15-Nova	1969	24
Medlab (CDC)	Pathlab	CDC1784/ Cybers 1800	1970	35 installed 5 back log
MCSI (Medical Computer Scientific International)	Gamma	Nova 800	1969	3
SI Medical (Systems Industries)	S/2000	PDP/11/34	1975	38
BD Spear	CLAS	Spear 12 bit/16 bit	1966	50
Technicicon T & T	LDM	Nova 2	1966	8
*Technicon T & T	(Purchased) (Loma Linda) System	DG-Super Novas-Front End S130 Eclipse	1978	3 Test Sites
Northrup	Northrup Data	PDP8	1972	?

*Please note the following on those marked with an asterisk.

Advanced Medical Systems (AMS) was formerly Automated Health Systems (AHS) until dropped by Cooper Laboratories in November 1973. Three of the four installations of AMS were AHS contracts, although Hahnemann in Philadelphia was installed by AMS after they changed the software. Hahnemann has reported experiencing response time problems. AMS recently signed Cedar Sinai in Los Angeles which is the only known contract they have signed and installed since the change over.

Berkeley Scientific Laboratories (BSL) was one of the early companies in this market. They were formerly owned by Tracor, then Northrup, and last by Health Guard. The company is currently operating as a privately held group, primarily employee owned, and is run by Ken Lame, who has seen them through many changes. Their early systems were on the DEC PDP8 of which there are fifty (50) systems operating including private laboratories. This would include the Northrup group as well. However, with the sale of BSL to Health Guard, Northrup kept the independent laboratory system which has a tendency to confuse the facts in terms of numbers of systems. BSL installed ten (10) of the Clinidata 700 series on the Tempo and then changed to the 710 on the CalData. They have installed ten (10) of these with eight (8) on back log, while experiencing the changes in ownership.

I.B.M. has three of the systems installed of the University of Alabama type.

Laboratory Computing, Inc. (LCI) was recently dropped by Brunswick. Their list of installations is somewhat confusing since they converted many former DEC Clinlab 12 customers to Labtron. The best available figures show 18 true LCI contracts and 22 DEC conversion for 40 systems. The company is now called Laboratory Consulting, Inc.

T & T Technicon has purchased the software from Loma Linda and has two or three pilot installations. The system uses the S130 Eclipse as the CPC and the DG Super Novas as the front end.

**The author has attempted to provide the most accurate data available to her. She welcomes any assistance in updating or editing this table by the readers.

The contrasting view concentrates on the professionals using the computer: physicians, nurses and technologists. According to this view, the cost of the professionals' time and attention outweighs the efficiencies contributed by automated computer operations within the laboratory. Systems designed on this basis achieve cost-effectiveness by conserving user intervention both within and outside the laboratory. This is achieved by good planning and careful systems analysis. The planner considers when and where laboratory documentation will normally be used, and then assures that preprinted reports go to the point of use.

Where should we go from here?

To answer that question, it may be useful to examine the concepts underlying computer system design. For 20 years, computer experts have focused their efforts exclusively on system designs that emphasize the technology: time-shared computers, real-time operation, on-line interfaces, direct data acquisition, high-level languages, data-base management and interactive program modification. Systems with these features have been offered by 24 vendors, including the major computer manufacturers. As mentioned earlier, nearly 300 laboratories in hospitals of all types have purchased such systems. In some, the laboratory system is integrated into a total hospital information system.

In contrast, only a very few laboratories have adopted the kind of innovative design alternatives that can no longer be neglected in a cost-conscious environment. Ways must be found to control laboratory expenses. We believe that parallel trails and objective evaluation of alternative computer systems in different types of hospital environments are now indicated. As the concerned laboratory professional comes to grips with the issues raised in this article, several groups are beginning to look at the situation in which computerized clinical laboratories find themselves. We hope you will share your concerns and suggestions with us and with the laboratory computing community. Everyone will profit from a constructive team approach to this problem.

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Question 3.

Would the development of such a proposed coordinated Health Information System significantly alter information flow in the hospital?

Drawing from the vast experience now available on the implementation of Hospital Information Systems it has already been shown that the introduction of Hospital Information Systems have had a major impact on the information flow, information management and patient management in hospitals. Many of these issues have been addressed and published in part as a result of a Technical Committee Workshop sponsored by the International Federation of Information Processing (IFIP) entitled, Hospital Information Systems -- An International Perspective on Problems and Prospects, edited by Dr. Roger H. Shannon, 1979.

Furthermore, the work being carried out by the Trimis people, and I make special reference to Dr. Rudi Bickel, have addressed the implications of a coordinated Health Information System for the three branches of the Armed Forces. Some of the experts in this field for further reference are: Dr. Donald Lindberg, Dr. David Mischelevich, Mr. Gary Hammon, Dr. Elemer Gabrieli, Dr. Octo Barnett, Dr. Larry Weed, Dr. Jane Elschepp and Dr. Alvan Fienstein.

Comments

An area which has not been addressed in the three questions posed is the enormous impact that Medical Information Systems on a national basis would have on concurrent review possibilities as opposed to retroactive review pertaining to patient care as it is provided by the physician. The implications for this are far-reaching and could have major implications for continuing medical education requirements, mandated in many states for relicensure, recertification and recredentialing.

Mr. SCHEUER. Our next witness will be Mr. Stanley Matek, who is the president elect of the American Public Health Association, a member of the board of directors of the American Health Planning Association, and a member of the California Board of Quality Assurance.

He is the author of several articles and a monograph on "Accountability in the Health Care Field." Mr. Matek has been a consultant to the Office of the Surgeon General and to the National Institutes of Health, National Institute of Mental Health. He has been active in the field of health planning for 15 years. We are happy to have you with us, Mr. Matek. Your testimony will be printed in full in the record.

STATEMENT OF STANLEY MATEK, PRESIDENT ELECT, AMERICAN PUBLIC HEALTH ASSOCIATION

Mr. MATEK. I will submit to staff a typed copy of some notes that I made last night. I will start by addressing the American Public Health Association's perspective on cooperative health statistics system; and then I will revert to my secondary role as health planner and address some of the other issues. The American Public Health Association has about 50,000 members virtually all of whom are regular users and generators of health statistics. We have been at the task of creating and applying health data for over 100 years now, so we have some experience in the field. We are strong supporters of the CHSS program. We think it is a good idea. We think it is definitely feasible and much needed. We think that it is needed more now than ever—especially when you talk about funding to State block grants, as you talk about limitations in funding for health services. We are very much concerned that we are not going to be able to make either the health status of the public, or the effectiveness of health services, or the economics of health care intelligible if we do not have comparable data bases built right from the health care institution to the county level, to the State level to the national level. We think data systems and especially coordinated data systems are part of essential infrastructure of public health and public policy. We think they are also a key resource for identification of private sector opportunities. We think they are a guide to the proper balancing of public sector and private sector roles in society in health matters.

We feel that while the idea of CHSS is sound, it has not yet worked the way we would like it to—primarily because of underfunding in view of the high startup cost and in view of the need for better incentives to get people to cooperate with this idea. Secondarily, it has not yet worked well because there have been turf problems within various bureaucracies that are compounded by underemphasis on the importance of State level record systems. We think this system can work, however, given the resources and the time. Looking at the mortality data in this country it took us over 25 years to get consistent minimum data for death certificates. We finally got it and we now have one of the best in the world. But just that one item took 25 years of negotiation and cooperation. It has given us an example, and it sets some experience levels that we think will entice people to be more cooperative more frequently in the future than they have in the past. But we do not want to underestimate the jurisdictional difficulties. We do not see many effective sticks in this business so we are looking frankly for more attractive carrots. That is why we feel there is a need for additional funding to support the startup and the implementation of the system. We do not think the problems are primarily technological. The technology is there. We are not using the technology to the potential it already has.

We think that the main problems lie in the realms of policy and jurisdiction. They lie in limitation of data uses to single program management rather than using them to gain an understanding, a sense of intelligibility the system as a whole. We think problems lie in this uneven awareness of the potential advantage of cooperation at the institutional level, county level, and State and Federal level. We think problems lie in fear about regulation. People are unwilling to give data because they are afraid it will be used against them. They do not see that it can be used to help them.

Mr. SCHEUER. Excuse me. Who has that reservation?

Mr. MATEK. I see that reservation in nearly every hospital I visit. I hear it from the Hospital Association and Medical Association all the time.

Mr. SCHEUER. You hear it from top hospital decisionmakers?

Mr. MATEK. Sure and from medical staffs. That is because they have been living in an environment where they have expected nothing but regulation and they do not see the opportunities in sharing data to help them do their jobs better.

Mr. SCHEUER. I do not wish to interrupt your positive testimony—and when we finish go on uninterrupted—but you have cut through the fat and muscle and have gotten to the bone. The big question is how do we encourage and nudge these top decisionmakers in the 7,000 American hospitals to view a comprehensive health information service as an aid to them, to make them look good, rather than as a threat to them and as a monitor? They perceive the computer as being a selfless, nameless, formless, inhuman, unhuman essence up there that is poking the finger of guilt and blame at them. How do we help them view this as something that will make them look good rather than something that will show them up for being a bunch of fumblers because they cannot retain 10 billion pieces of information in their brains as a computer can?

Mr. MATEK. There is no single answer. You have to look to who is complaining and why and how they operate, what their style is and where they are located in the system.

Mr. SCHEUER. When you finish your affirmative testimony I hope you will turn to this question.

Mr. MATEK. I will.

Mr. SCHEUER. Elaborate on that because this is what it is all about. This is what is frustrating us beyond measure.

Mr. MATEK. Let us follow it now. I think if you engage in more marketing of success stories, and if you engage in more marketing to various constituencies on how cooperative data systems can help them do their job better, save money, ease management loads, then I think you will get some responsiveness. But you will not get it from everybody. The trade associations will be the last people to respond positively to what you are offering. The trade association is bound to represent the majority of its members, and tends to represent the lowest common denominator of membership opinion; so you have to divide and conquer. You have to go to the most responsive individuals, and eventually success breeds success. I think Dr. Ball was right; you start with the people that are doing it, and then you start marketing.

Most hospital administrators are not the key decisionmakers in the institutions. They are the victims of pressures primarily from constituencies in the medical staffs. It is doctors who exercise the political muscle in hospitals, and the administrators who serve as mediators. So, the administrator cannot always be the decisionmaker. You may have to market to doctors. And you do not market to all doctors; you market to the leaders. In some institutions the leaders are very dedicated professional people. In other institutions they are interested primarily in either their own department, or their stock portfolio. And it varies.

Most professionals can be appealed to on the basis of high professional values and service. You have to overcome the inertia of the status quo, and you have to overcome input overload.

I think the leadership service that can be provided by the National Center would lie in cooperation with various institutions or—if you can get it—with the AMA and AHA in joint marketing of success stories on data systems in patient care, in management, in economics and in understanding of the health status of the local population. If I could take St. Judes Hospital in Fullerton, Calif., for example, if I could get their patient origin data and their case mix data and combine it with what I already knew about their cost profile, and combine that with what the health department knows about the health status of the people in Fullerton, then we could show not only the hospital and medical staff but the city council and county board of supervisors two things: one, how good a job St. Judes is doing; and two, how to do it better. But we cannot get those data streams coordinated yet. That is the commission of CHSS.

If we could get more honey in the salad dressing and not so much vinegar, I think we could make it happen. If you make it happen at St. Judes I can show you five other hospitals that would follow. And eventually I could show you another 10 that would follow. It will take 15 years for the last 10 to follow.

Mr. WEBER. Will the chairman yield?

Mr. SCHEUER. Surely.

Mr. WEBER. Dr. Ball indicated in her testimony that the nursing profession appears to be somewhat enthusiastic about this idea. Is that your understanding as well?

Mr. MATEK. I do a lot of public speaking and I have found nurses to be the most creative, most flexible, and most ambitious of all the health professions.

Mr. WEBER. You must be married to one.

Mr. MATEK. As a matter of fact I am not.

Mr. WEBER. Can I take what you said a step further—is there considerable resistance from physicians and hospital administrators or from either of those?

Mr. MATEK. Yes, there is resistance.

Mr. WEBER. From both those groups?

Mr. **Matek**. Yes. It comes from several groups. As Dr. Ball pointed out there is wide acceptance of the use of computer technology for billing. That is related to money and to cash flow and turnaround—things which help management deal with what management has to worry about: the bottom line. There is a lot of resistance among physicians, and some of it is because they do not have time to learn new things. In my field, one of the major fears is that computer technology will violate confidentiality—not primarily patient confidentiality, but physician confidentiality. They do not want somebody telling them they are doing the job incorrectly or inadequately.

Mr. **Weber**. It occurs to me, Mr. Chairman, that will be a very fundamental problem. Regardless of the benefits to the public health at large you are really fundamentally altering the role of the physician here. All of a sudden instead of being the lord in his fiefdom he is taking orders from a computer or at least having to put his own judgement to the test. That really may be for the better but it is basically changing the role of the physician.

Mr. **Matek**. It appears to be that. But it is not really the case.

Mr. **Scheuer**. It is giving the physician enormous aid and support staff. Should not the doctor perceive of his computer as a vast staff all plugged in to his brain, each one of 10,000 experts with a million pieces of information, each one of them shutting off the other and plugging in when the information he provides is relevant.

Mr. **Matek**. The answer to your question is yes.

Mr. **Scheuer**. I do not mean to put words in your mouth, but I presume your question is how do we get these health professionals around the country who are concerned with their stockbrokers and investments, concerned with ego and concerned with face, to perceive of the computer input that can help them with a far higher level of professionalism in their diagnosis and treatment? How do we get them to perceive of this as an assist to them in helping them vastly improve their memory, vastly improve their ability to coordinate and distill and analyze a million different facts that the human mind unaided cannot do? This is a question we have asked the two preceding witnesses. How do we get them to look at these systems as something that can enhance their professionalism and enhance their ability to provide excellence of patient care at a minimum cost rather than viewing it as a threat to them as something that demeans them and reduces them professionally?

Mr. **Matek**. I guess the easiest way to do it would be to get some doctors to start selling the idea. I know a doctor in Orange County, Larry Stoneburnner—coming from a very conservative approach where the doctor really is the sole and exclusive decisionmaker in all matters—has adopted computer technology and is now trying to sell it to other doctors. You will hear from Dr. Gabrielli, an M.D., who uses it and is willing to try to sell it to other doctors. I think as far as marketing these ideas you have to have multiple approaches, and lots of repetition. New news is scary news; and by and large the only time a thing becomes credible is when it sounds like old news. So I think repetition is not only the mother of studies, but the mother of marketing. We have to market the stuff until it becomes less scary than it is now.

Mr. **Weber**. It occurs to me that the most important thing is to convince them that it is not only for the common good but if there was some financial benefit to them as well that might be helpful. What occurs to me is the area of malpractice insurance. Have the insurance companies shown any indication of adjusting the malpractice premiums for a doctor that may have these tools at his disposal?

Mr. **Matek**. To my knowledge, no.

Mr. **Weber**. So there is no financial inducement in that regard?

Mr. **Matek**. No. As a matter of fact the initial inducements do not seem to be financial. They appear to be a matter of convenience, or magnification of professional competence. It is the more altruistic values which seem to be involved. At the hospital level, finance is the key motive. And at the State level it is neither finance nor individual medical practice. It is public health and biostatistical profiles. All of these considerations are essential.

For Government I think all this has to relate to cost and policy and choices. Right now we tend to homogenize our approaches. If we had a multiple-stream data base we could target our policies and our resources, and we would not have to rely on clumsy regulation because we could target projects. In Milwaukee, for example, we identified through a special study that there was a significant profile on lead poisoning in kids. It followed age of housing and freeways and we could target the use of our public health nurses based on what we saw on the printout of the statistics on lead poisoning in kids. Then we did not have to send the nurse to every home in an area to check out lead poisoning. We only had to send her to a tenth of them.

Mr. **Weber**. I certainly do not question what you are saying but for my own information I want to follow my original point up one more step. It just occurs to me that a physician who has at his disposal tools that will lessen the probability of his making a mistake—it seems to me insurance companies should take that into account or at least there is some basis for considering that that physician is a better risk than a physician that does not have those tools. Explain to me why no insurance companies see that.

Mr. **Matek**. Because there is not data to prove it. Nobody has looked at the question, and correlated the data to find out. We do have correlated data—we know people who do not smoke are better risks as drivers and as health insurees. But we have never correlated physician use of computers to malpractice insurance suits. That is a question that could be posed to the industry. If you could get the industry to check on it, and if they find actuarial correlations that work, then they will grant the differential.

Mr. **Scheuer**. Is there enough information in our computer to verify statistically in a way that would impress the insurance companies that physicians who are computer assisted, who have the benefit of computer terminals in their analysis of patient needs, and in their patient diagnosis—to prove they do a significantly better job to obtain higher levels of health care than physicians who do not have that capability?

Mr. **Matek**. To my knowledge there is no such evidence yet. Perhaps Dr. Gabrielli can address that when he gets up here. He will know more about it than I would. I have seen no data or know of any data collection system that even asks that question.

Mr. **Scheuer**. Dr. Ball, are you still with us?

Dr. **Ball**. Yes, sir.

Mr. **Scheuer**. Could you give us any judgment as to whether you could do an analysis now of actual diagnostic experience comparing physicians who have this computer assistance in their diagnosis compared to physicians who do not? Is there enough data in the computer bank nationally speaking to make a credible case that physicians who are computer assisted in their diagnosis and treatment do a better job of patient care, perhaps as cheap or even cheaper than physicians who do not have that assistance?

Dr. **Ball**. I would say yes to that question.

Mr. **Scheuer**. We will be asking you later on to help us make that case. If it can be made I would think as an educational device it would be extremely effective. I yield back.

Mr. **Weber**. Thank you, Mr. Chairman. I have one final question. I think I know the answer but I would like you to confirm it. If we did see a situation developing where malpractice premiums were adjusted based on the availability of computer technology to the physician, is it your belief that that would be a strong enough incentive to change the attitudes of many people in the medical community?

Dr. **Matek**. By itself I would have to say maybe. My experience with malpractice premiums were they were much complained about but last year one of the major insurance companies returned astronomical amounts of money, something in the area of $84 million to California practitioners in excessive premiums. The premium costs have been in the meantime passed down to patients. That money does not go back to patients. It was redistributed to doctors. Hospitals have set up their own insurance companies and medical associations have set up their own insurance companies to mitigate the impact of malpractice insurance. There is a company set up operating out of Bermuda which has drastically lowered the cost in southern California. It was set up by a Long Beach hospital. One level is not going to work. You have to have your hands on more than one level.

Mr. **Weber**. I have no further questions.

Mr. **Scheuer**. Continue if you would.

Mr. **Matek**. In general, gentlemen, I think we are at a point where we need to maintain continuity of effort. I think you need more funding for the CHSS system to get us over the startup hump. I think we have to provide not only incentives but more rapid feedback to cooperating groups. One of the problems is that CHSS has taken data in. They have set up the machinery and set up the coding. They distributed machinery and collected data and now they are coordinating data. But so far nobody has seen the data come back—at least not many have. So there is no sense that all the work is yielding results.

The fact is that data collection is no fun. The only fun about a data system is getting results back, and discovering something you did not know before, and be able to use it. We have to get some fun out of this process; and we have not done that yet. If we do, if we emphasize State level productivity more—because really the State level data collection systems is the core of making this work—then I think we will get results. If we provide the marketing of success stories; if we provide the training for the input work and the training models. If we provide as a service or as an incentive the computer programming; if we provide standardized screens so that they can be operationalized at a hospital level or at a county level so clinics can use those screens to coordinate their internal data systems with the higher screening systems; if we can guarantee patient confidentiality, and physician confidentiality and if we start producing data profiles which mean something to our practitioners, then we will succeed.

I can show you success stories gentlemen. I am using now in Orange County some material in child health data, Dr. Ronald Williams put together with title 5 grant. This data tells us about neonatality about newborn kids: whether they are the first child or multiparas. It shows us birth weight, race, date of birth, all by hospital. It gives the hospital's perinatal mortality rate by year, and allows us to reach conclusions about individual hospital practice. We can make conclusions about how to regionalize care, how to provide better services to obstetrical patients in individual hospitals. We can look at patient education by race, by target group, by geographical subarea. All of this comes right off our standard birth certificate information. It is a program which has never been implemented until Ron Williams got the special grant. It has now been implemented in California. But Williams has run out of money. We need a way to maintain this program and give it to other people.

CHSS can meet this need. It is a perfect example of how birth certificate data can be standardized, can be combined, can be diffused and used in every county in the Nation to tell people how their hospitals are doing in perinatology, how their practitioners are doing, what the cost benefits are, what the age, race, geographic distribution and health status needs are. Our medical association, after initial resistance, has gone along with this. We now have regionalized perinatal services and intensive care services in Orange County as a result of this work. This is the kind of thing that will make an economic difference.

I just came back from Anchorage, Alaska. We had a high mortality rate there for neonates. We identified one hospital in Anchorage. We sent in a neotologist and in 2 years he brought that rate down to less than half of what it was before. That becomes cost beneficial because you are not only talking about prevention of infant death, but especially the prevention of permanent handicaps. This is the kind of thing that gets public health professionals excited and makes every pediatrician and OBGYN man stand up and take notice.

Here is an article I found in the paper, "Cancer. Twisting the Statistics About its Causes." The issue is this: Are carcinogens in the workplace causing cancer, or is it smoking and other personal health habits. The article maintains industry is trying to emphasize personal health habits, and deemphasize the carcinogens in the workplace. It seems as public policymakers we need to know the data, and we need sound data systems for that. You have to worry about budgets and claims on medicare and medicaid. Also, you are now talking about State block grants. States have to worry about where the money is going. Those decisions cannot be made without comparable data streams.

So it seems to me that the future issues facing us as policymakers as well as health care providers means we need to have coordinated data systems. The cost of starting and maintaining the systems is simply part of the cost of doing business. It is not a luxury or an academic pursuit. It is an issue of basic economics and managment. I think the resistances can be overcome to the extent we make clear that it is an economic issue, and the patient begins to understand that our failure to manage well means money out of his or her pocket, money out of insurance companies pools, and money out of the employer's pocket. I think what Dr. Ball had to say and what Dr. Gabrielli will show you will confirm that the possibilities for real progress are there. Now my question to you is, how much of a carrot can you make available?

Mr. Brown.

Mr. BROWN. Mr. Matek, I missed most of your testimony and I apologize for that but your last remarks with regard to the significance of having birth certificates in a usable form raises in my mind the question of whether or not this would be a reasonable target to set as a national program. That is having national system computerized, standardized birth certificate data that would give us the tools needed to do some of the things you have referred to. Incidentially if we do not have a copy of that article I would like to see it.

Mr. MATEK. I will leave these for you.

Mr. BROWN. If it would be reasonable to do that, and we start it now, possibly just as with the index program we might be able to develop a birth index and a system of birth certificate data that would give us the two ends of the spectrum, birth and death and then we could fill in between. Is that a reasonable part of a goal for health information systems?

Mr. MATEK. Yes, Congressman, it is. What is more, the basic capability already is available even in your own area. In Riverside and San Bernadino counties they are trying to get this same job done. All that is needed is the ability to computerize the birth certificate data, and then to put it on line so it can be printed out. The computer program is already developed. All you have to do is implement that program and get the processed data back. Then, you give it not only to the county health department, you give it also to the health planning agency and to every hospital. You give it to the hospital association, the medical association, the pediatrics group, the OBGYN group, and the newspapers.

Mr. BROWN. When you say they are trying to do this in Riverside and San Bernadino you mean the county health department in those counties?

Mr. MATEK. The health systems agency there is working on the regionalization of perinatal care the way we are in Orange County. We were the first ones to run with this because we budgeted a lot of staff time to get it done. If we could just get every county's birth system computerized, every county in the United States could have this. It is a distribution issue and it is a motivation issue. It is a question of overcoming the sense of territoriality and getting them to see the higher good. To me it is a leadership issue.

Mr. **Brown**. You represent the Health Systems Planning Agency in Orange County?

Mr. **Matek**. Yes, I do.

Mr. **Brown**. Has it been your experience not the health system planning agency in your experience is a viable vehicle for achieving those kinds of changes which would benefit the efficiency and effectiveness of health delivery systems and hopefully be cost-effective as well? My impression is that we set up health systems planning agencies for that purpose. Yet I find a large number of health systems planning agencies do not really see their role in those terms.

Mr. **Matek**. Yes, they were set up for that purpose and then were given a lot of additional jobs to do which muddied the waters and confused the picture. The data base is only now beginning to become available. For years we had no access to the data, which was jealously guarded by individual institutions. Now in California we have the health facilities commission; so for the first time we have financial data that is comparable. We also have this Williams data; so for the first time hospital performance relative to birth by race and age is available. For the first time the mortality data is becoming available by subarea. We are just at the beginning of these technological breakthroughs, and planning is just now at the point where it could shift from being primarily a matter of politics and rhetoric to primarily a matter of data and technical assistance. Planning should not be involved in my judgment in the mixed bag of assignments that have been given to HSA's. I think you could redefine health planning and get good results. If you do not redefine it you may keep getting mish mash.

Mr. **Brown**. I have no further questions, Mr. Chairman.

Mr. **Scheuer**. Who should be in charge of that redesign and where should that take place?

Mr. **Matek**. The design has to have elements of standardization. I would look to the Federal level, but in cooperation with the States.

Mr. **Scheuer**. The Federal level is wide.

Mr. **Matek**. I think NCHS is a good starting point; but there have been jurisdictional battles. Because they have not had time or funding or clear priority, other departments have picked up in the interim. HCFA has done separate things because they had to get going with their work. They could not wait. That is one reason I called for more adequate funding so we can overcome the unavailability of staff time and technical resources.

Mr. **Scheuer**. I take it there are pieces of a coordinated health information system in place?

Mr. **Matek**. Yes, sir.

Mr. **Scheuer**. What pieces are missing, how would you propose filling in the gaps and who should be responsible for designing the system by which we fill in the gaps and create a comprehensive health information system?

Mr. **Matek**. Frankly all of the basics are already pretty much in place. It just has not operated rapidly because there has been so much resistance. The National Center for Health Statistics has the game plan. They have the program, and the sets of data streams. They have started working with the States. They have put out the request for information and the data has come back albeit sometimes as much as 2 years late.

Mr. **Scheuer**. Is it on a voluntary basis?

Mr. **Matek**. Practically speaking, yes. Current regulations and mandates are honored as much in the breach as in the fulfillment. That is part of the leadership and turf problems.

Mr. **Scheuer**. If we hooked the granting of certain funds to the States to their prompt provision of these requests for collection of data, provision of data, would that help concentrate their minds?

Mr. **Matek**. In some States.

Mr. **Scheuer**. A condition precedent to their getting certain kinds of perhaps additional funding to help them put this system in place.

Mr. **Matek**. The additional funding would be more attractive than the imposition of a requirement which says if you do not do it we will not give you any money. I have seen that strategy fail repeatedly in California, for example. California—especially now—feels it does not have to pay attention to bureaucrats' requirements. After all, we have a President. I have watched California for 3 years delay State level implementation of health planning, and succeed, even against a congressional threat of the withdrawal of Public Health Service funds. We delayed that sanction every year. To my mind the carrot is much more effective than the stick as an approach.

Mr. **Scheuer**. Why have they been stonewalling in effect?

Mr. **Matek**. Basically because the closer you get to the local level and especially the individual institutional level, the more vociferous and vehement become the resistances.

Mr. **Scheuer**. Why?

Mr. **Matek**. The resistance to is to disclosure. The charge is that you are adding additional disclosure and accountability requirements which cost money and time. That is why we have to walk in there with a streamlined program and say "Here, we will give it to you. All we are asking for is coordination." Every hospital has their own data collection system but it is designed to be individual. They have their own fiscal years so they are noncomparable on costs. They have their own approach to organizing their departments. Achieving uniform data is made difficult because comparable data is threatening. What providers need to understand is the service potential and frankly the economic advantage potentials in cooperating. The old Latin proverb says, You can do more with sweetness and savvy than with muscle. St. Francis mentioned it was a spoonful of honey or was that Mary Poppins?

Mr. **Scheuer**. I would like you to submit some recommendations if you would as to how we can prove success both on an institutional basis, hospital by hospital, and on an individual physician basis. How we can show them this is an enhancement of their capability. We are going to help them achieve a higher level of professionalism. We are going to help them overcome the limitation of the human mind. We cannot hold 10 billion pieces of information in our mind and retrieve them and apply to the individual the conditions and needs, of an individual patient. That is beyond the capability of the human mind but it is not beyond the capability of the computer. We can factor in other questions, understanding of patients, psychological, social, and family needs, and there is a very noble function for a doctor to play at the highest level of professionalism using this computer as an assist to him. We are enhancing their capability of excellence. After all, to some extent they are also concerned with that too, I presume.

Mr. **Matek**. Are AMA and AHA represented here? Those are two sources to ask that question of. And I will take on the job of doing it Dr. Katz can do the same thing. Yes, it can be done.

[The prepared statement of Mr. Matek follows:]

TESTIMONY BEFORE THE HOUSE COMMITTEE ON SCIENCE AND TECHNOLOGY

Stanley J. Matek

June 2, 1981

Gentlemen:

My purpose today is to let you know in five minutes where the American Public Health Association (APHA) stands on the issue of the Cooperative Health Statistics System, and why.

APHA is a 50,000-member Association of public health professionals, virtually all of whom are regular users -- and generators -- of health statistics. We have been at the task of creating and applying health data for 109 years, so we think we know something about the uses of health statistics and the problems involved in generating them.

We have been strong supporters of the Cooperative Health Statistics System since its conception, and we continue to regard it as much needed, as governmentally appropriate, and as definitely feasible.

The System is sound in concept and design. But it has not yet worked the way we would like it to. There are two basic reasons for this: first, underfunding especially in view of the high start-up costs involved, and the need for incentives); and second, turf battles within various bureaucracies, compounded by an underemphasis on the importance of state level record systems.

Neither of these problems are insuperable. The System definitely can work, given the resources and the time. (It took 25 years to fully coordinate a minimum data set for death certificates in this country; but now we have the best mortality statistics system in the world.)

The problems which limit our progress are not primarily technological. The technology is there; it is ready for application, right from the doctor's office and the hospital record room on up. The problems lie in the realms of policy and jurisdiction. They lie in the limitation of data uses to single program purposes; they lie in uneven awareness of the potential advantages of cooperation; they lie in fears about regulation or preemption or even just fears of work burdens without rewards.

To overcome these problems, we do not need novel solutions. Fundamentally, we need two familiar things: adequate funding and adequate leadership. The funding must be sufficient enough from now on to include incentives and feedback benefits to cooperating groups -- features which have not yet become sufficiently characteristic of the System. And the leadership must be large-spirited enough to focus attention not on technical problems as obstacles to movement, but on immediately realizable results as leverage for next-step developments.

Let me show you what I mean. Here I have a report on perinatal morbidity and mortality, and on related maternal health indicators by age, race and number of children. This data is refined right down to the caseloads of individual hospitals in Orange County, California. It was compiled from bith certificate information, using techniques and computer programming designed by Dr. Ron Williams, and jointly funded through the State of California and a Title V Maternal and Child Health grant. It has vastly improved our local ability to do institution-specific, population-specific and service-specific health planning, and even to begin performance evaluation of health service units. Now that the processing program has been devised, all that is needed to widely diffuse similar data is the application of the program package to computerized birth certificate information.

It is the kind of effort which could produce rapid and evident benefits, which in themselves would serve as incentives to further cooperation and progress at state and local levels.

The report I have cited, and which I will leave for incorporation into your record, is technical in nature, and exciting primarily to statisticians, planners and maternal and child health professionals. But excitement over results from the Cooperative Health Statistics System need not be limited to health professionals. Elected officials and other policymakers can benefit also -- especially when vital statistics are seen in conjunction with morbidity data, cost data, and hospital, clinic or nursing home data. We will then be able to really target our programs and our money, and to trace the consequences. This can have important short-term benefits -- for the management of block grant programs, for example, or for the development of productivity and impact indicators. In broader terms, what we are talking about is a data base which will help us take more refined and responsible approaches to environmental and occupational problems, to manpower programs, to health economics, and to the health status of our people.

We know full well that this is not all achievable immediately; but the feasibility of the program has been demonstrated. The single most important success factor now is a firm DHSS commitment to consistent, reliable efforts over time. What APHA is here to do, gentlemen, is urge that you and the Department take the necessary next steps, and do so promptly: NCHS has already moved from coordination and machine distribution to data acquisition and consolidation; now it must move on quickly to data *distribution*, and to the addition of the next data sets. The funding levels must be improved. Emphasis must be put on the development of strong state level systems. Provider associations must be drawn constructively into the process, and there must be a constant sharing of results. The federal level must become a training and technical assistance resource, a *leadership* resource. APHA will support these next steps, and would love to help.

VITAL RECORD DATA FOR USE IN THE PLANNING OF PERINATAL HEALTH SERVICES

by

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Produced In Cooperation With:

Maternal and Infant Health Unit,
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PREFACE

This report describes and analyzes information derived from California's matched live birth, infant death, and fetal death files. The data are maintained in the Maternal and Child Health Data Base at the University of California, Santa Barbara under the auspices of the Maternal and Child Health Branch, California Department of Health Services. Ronald L. Williams, Ph.D., designed and manages the data base, and has been working with it since 1976 in developing a statistical index capable of measuring the effectiveness of obstetric and newborn care.

Because the data base was organized for Dr. Williams' research to provide information at the individual hospital level, it has recently become apparent that the data might be of value to Health Service Agency (HSA) and Office of Statewide Health Planning and Development (OSHPD) staffs in California who are seeking data for Appropriateness Review. HSA's are currently moving from area-wide analysis to individual institutions, and perinatal care is their first priority. Consequently, at the request of the HSA/OSHPD Perinatal Workgroup, two workshops, sponsored by the Western Center for Health Planning, are to be held in early April 1980 to present and explain the data in this report to HSA staffs. The report contains general data for explanatory purposes, but is supplemented by appendixes containing specific information for each individual HSA. Thus, there are 14 separate reports, one for each of California's 14 HSA's. Additional copies of reports for specific HSA's are available from local HSA offices.

Warren E. Hawes, M.D., Chief
Maternal and Infant Health Unit

Kay Moser, Chief
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The contributions of the staff of the California Department of Health Services in developing the Maternal and Child Health Data Base is gratefully acknowledged. From the Maternal and Child Health Branch, the project has benefited immensely from the efforts of Drs. Warren Hawes, George Cunningham, and Joseph Brazie. Gathering information from vital record files would not have been possible without the sustained contributions of Frank Norris and Mich Tashiro from the Center for Health Statistics.

Gratitude is also expressed to the following individuals who helped in organizing the dissemination activities: Dr. Allan Voigt, Holland Golec, and Ruben Gonzalez of the Office of Statewide Health Planning and Development, as well as Jane Walsh from the Western Center for Health Planning. Additionally, many persons from California's fourteen HSA's assisted in improving the reporting format.

I am indebted to many individuals at UCSB who helped to produce this report, including, but not limited to: James Membrez, Peter Chen, John Marinko, and Barbara Hagen of the Community and Organization Research Institute, as well as Glenn Davis of the Computer Center.

Major funding for the project was provided by the Bureau of Community Health Services, DHEW, with additional support from the Maternal and Child Health Branch, California Department of Health Services.

Ronald L. Williams

I. INTRODUCTION

The decade of the 1970's witnessed widespread and dramatic changes in the realm of maternal and infant health. Ranging from an accelerated rate of technological intervention in the birth process, to the increased availability of family planning and liberalized abortions, to changes in family size and marital bonds, and to a renewed interest in a family-centered approach to birthing, these changes have been diverse and rapid in their pace. During this period more liberal Medi-Cal eligibility requirements doubled the proportion of mothers covered by the program from 15 percent to 32 percent. Coincidentally there has been a sharp decrease in perinatal mortality. A backdrop for these events has been an unprecedented increase in medical care costs, the ongoing debate over national health insurance, the enactment of P.L. 93-641 mandating the formation of Health Systems Agencies (HSA's), a national movement toward the regionalization of perinatal health services, and, finally, the passage of California's Proposition 13.

The rapidity of change has emphasized the need for statistical data which can be used by both planners and providers. While traditionally-reported vital statistics still provide valuable information, it has become apparent that more elaborate methods of analyses should be employed. Fortunately, there were also rapid advances in computer technology and applied statistical methods during the 1970's, making possible the monitoring of maternal and infant health over wide geographical areas at a reasonable cost. Thus it was that the Maternal and Child Health Branch and the Community and Organization Research Institute established a cooperative perinatal health research project in 1976. The project, which was funded by the Bureau of Community Health Services, DHEW, had as its principal objective the development of a statistical index capable of measuring the efficacy of obstetric and newborn care; hence its title "Measuring the Effectiveness of Perinatal Medical Care."

The primary sources of research data were the linked vital record files compiled on computer tape by the State Department of Health Services. Starting with the 1966 through 1970 cohorts, a computerized data base was established at the University of California, Santa Barbara. Gradually, the data base was expanded to incorporate all available linked record cohorts. At present the Maternal and Child Health Data Base (MCHDB) contains the 1960 and 1965 through 1977 birth cohorts comprising nearly 5 million records. Although the total file was very useful in completing the research objectives, emphasis was given to the 1970-1977 cohorts. During 1978 and 1979 the research methods and results were subjected to professional peer review and were reported in scientific journals [1,2,3]. Presentations describing the MCHDB were made to lay and medical groups and constructive suggestions were received, resulting in improvements in its usefulness.

As it became more apparent that the information contained in the MCHDB could be of value in the monitoring and planning of perinatal health services, legal opinion was sought concerning the advisability of making results available for public use. Legal clearance was obtained on October 9, 1979, and a report was then written describing the portion of the MCHDB related to HSA-5. After the report had been circulated among interested parties throughout the state, an ad-hoc committee convened on December 7, 1979 to evaluate the report and make recommendations regarding future dissemination. It was recommended that:

(1) The data should be reported on an HSA-specific basis.

(2) The written narrative for the report describing the statistical methods and giving examples on the proper interpretation of the data would be identical for each HSA.

(3) Two workshops would be arranged to present the report to HSA staffmembers, and instruct them as to its use and interpretation.

(4) Other interested parties could gain access to the data through their own HSA.

This, then, is the resultant product.

II. STATISTICAL METHODS

A. The Etiology of Perinatal Mortality

The MCHDB is founded on the principle that birth weight is the key intervening variable linking the intrauterine environment with perinatal outcome; no other variable is as predictive of perinatal mortality and morbidity. Birth weight, in turn, has been found to be associated with such maternal factors as socioeconomic and psychosocial status, ethnicity, maternal age and parity, marital status, prenatal care, medical history, and complications of pregnancy. Although the relationship between a multitude of maternal factors and birth weight is only partially understood, the accumulated evidence is suggestive of many elements combining to produce an intrauterine environment capable of supporting fetal growth at varying levels. For example, a 24 year-old white, middle-class married woman having her second child with no historical or current medical complications is more likely to provide an optimum intrauterine environment and hence a full-term, normal-weight fetus than a 16 year-old black, unwed adolescent in her first pregnancy who smokes and comes from a lower economic stratum. Of course these are extreme examples, and in actuality there is a wide spectrum of maternal attributes leading to a diversity of fetal growth characteristics.

Although the link between maternal factors and fetal growth is poorly understood, the relationship between fetal growth, birth weight, and perinatal mortality is more concrete. Figure 1 reports perinatal mortality rates per 1000 births, jointly dependent on birth weight and gestational age, for the total population (2,243,853) of singleton births in California from 1970 through 1976. Superimposed are the 10th, 50th, and 90th percentiles of birth weight at fixed gestations. A "normal" intrauterine growth path is described by the 50th percentile. It is generally agreed that babies born before the 38th week are "preterm," while those born after the 42nd week are "postterm."

Low birth weight (LBW), i.e., < 2501 g, is thought to be the result of two distinct phenomena:

(1) the fetus may follow a normal growth path but be preterm, or

(2) the fetus may be term (or even postterm) and be small for its gestational age (SGA), i.e., fall below the 10th percentile.

The latter case is referred to as intrauterine growth retardation (IUGR). Of course, combinations of both phenomena can also occur. Thus, it is theorized that adverse maternal factors create a disadvantageous environment for fetal growth, resulting in an increased probability of a preterm or SGA fetus and hence LBW. Included are maternal medical complications such as cardiovascular and renal disease, obstetrical complications such as antepartum hemorrhage, pre-eclampsia, and low weight gain during pregnancy, or health-related habits such as smoking, drug addiction, or poor nutrition. Maternal age, parity, marital status, ethnicity and pregnancy spacing are also believed to influence birth weight and gestational age. And while there is little substantive evidence, it is also thought that timely and skillful prenatal care can help to optimize the uterine environment and thereby increase the likelihood of normal fetal development.

The profound impact of birth weight on perinatal survival is immediately apparent in Figure 1. Perinatal mortality rates vary from 800-900 per 1000 for very small preterm infants to 2-4 per 1000 for normal size term infants. The overall perinatal mortality rate for this sample was 19 per 1000, demonstrating that total mortality could be lowered significantly if more babies were born at term with normal birth weights. Perinatal mortality is also highly dependent on gestational age; however this result is largely due to birth weight since for any birth weight group the effect of increasing gestation is not of great magnitude. Birth weight can therefore be considered to be the "dominant" variable.

Figure 2 presents equivalent data for all *multiple* births occurring during the same period (n = 44,953). It is immediately apparent that, by singleton standards, many multiples are SGA, and, as marked by the "X" on each plot, the average birth weight for multiples (2,378 g) is much lower than for singletons (3,333 g). Because each multiple fetus must share with its companion(s) the available nutrient material available in the placenta, the intrauterine environment is much less than optimal, and IUGR is very likely. The incidence of preterm birth is also increased as indicated by the lower mean gestational age of 36.7 weeks versus 39.6 weeks for singletons. These results are, of course, not unexpected. However, when the birth weight-specific mortality rates for all gestations (tabulated along the right-hand margin of each figure) are compared, a somewhat surprising difference occurs. We see that below 2501 g the birth weight-specific mortality rates are *lower* for multiples than for singletons. Thus, though multiples have a higher incidence of LBW, they nevertheless have a lower perinatal mortality rate when they are LBW. Even more interesting is the fact that similar differences are observed by ethnicity. That is, there is evidence of intrauterine growth retardation among disadvantaged ethnic groups, but their LBW mortality rates are also lower. Differences in birth weight-specific mortality rates are also observed according to the sex of the fetus, with females having lower mortality rates for most birth weight groups. Note however, that the lower birth weight-specific mortality rates do not compensate for the increased incidence of LBW among multiples since their overall perinatal mortality rate is nearly five times (101.6 per 1000) that of singletons (20.6 per 1000).

Figures 1 and 2 serve to demonstrate the extreme variation in the risk of perinatal death conditional on birth weight, and to a lesser extent on gestational age. As will be described below, the strong link between birth weight and perinatal outcome will be used to develop an index of the effectiveness of intra- and postpartum care for hospitals and geographic regions.

B. Statistical Background

The crude or observed perinatal mortality rate (OBPMR) has traditionally been used to compare perinatal outcomes for different units of observation. However, unadjusted rates may be misleading due to wide variations in newborn risk profiles, and as a result of chance occurrence. Conceptually, we partition the variation in OBPMR into three components:

(1) That resulting from newborn risk differentials (risk component).

(2) That attributable to chance (sampling component).

(3) That attributable to differences in intra- and postpartum care (care component).

Thus, if we wish to evaluate the care component for a particular hospital or region, we must first account for the risk and sampling components.

We now discuss the sampling component, which is based on elementary statistical principles. Let us assume that there is absolutely *no* variation in newborn risk differentials. Further, we will assume that all hospitals and/or geographic regions are equally effective in preventing perinatal death for a given level of risk. Under these conditions the underlying probability of death (π) is constant for all births in all hospitals and regions. Expressed as a rate per 1000 births, we refer to π as the expected perinatal mortality rate (EXPMR). For a unit of observation (UO), e.g., a hospital, city, or county, having n births, each with π as the probability of death, the probability of observing exactly x deaths is given by the binomial distribution:

$$P(x) = \left[\frac{n!}{x!(n-x)!}\right]\pi^{x}(1-\pi)^{n-x}$$

Note:

$$x! = x\cdot(x-1)\cdot(x-2)\cdots 3\cdot 2\cdot 1, \textit{ called } x \textit{ factoral.}$$

The *mean or expected* number of deaths for n births is given by

$$E(x) = n\pi$$

where $E(x)$ denotes *the expected value of x.* The variance in the expected number of deaths is

$$VAR(x) = n\pi(1-\pi).$$

To obtain the OBPMR for a UO of size n, we divide x by N (where N = n/1000):

$$OBPMR = x/N$$

or in probabilities

$$p = x/n.$$

But, since x is a random variable described by the binomial distribution, OBPMR (or p) can vary across UO's, even though EXPMR (or π) is constant. The expected or mean p for a UO of n births is

$$E(p) = \frac{E(x)}{n} = \frac{E(x)}{n} = \frac{n\pi}{n} = \pi.$$

Thus, the mean p (or OBPMR) is equal to π (or EXPMR) regardless of sample size. The variance of p is given by

$$VAR(p) = VAR(x/n) = VAR(x)/n^2 = n\pi(1-\pi)/n^2 = \pi(1-\pi)/n.$$

Note that, as contrasted to the mean, the variance of p (and also OBPMR) *is* dependent on n: i.e., as the sample size increases the variance decreases. Note also, that under our assumption of constant π, given that π is defined as the probability of perinatal death, we have $\pi — 0$ and $(1-\pi) — 1$ so that

$$VAR(p) — \pi/n$$

That is, for a constant π the variance in p (or OBPMR) is inversely proportional to the sample size n (or N).

Indeed, for small π and large n it can be shown that the binomial distribution is approximated by the more tractable Poisson distribution:

$$P(x) = \mu^x \frac{e^{-\mu}}{x!}$$

where $\mu = n\pi$. An interesting characteristic of the Poisson is that its features are described by the single parameter, μ, which describes both the mean and the variance of the distribution, i.e.,

$$E(x) = \mu$$

and

$$VAR(x) = \mu$$

Thus, for a Poisson distribution

$$E(p) = \frac{E(x)}{n} = \frac{\mu}{n} = \frac{n\pi}{n} = \pi$$

and

$$VAR(p) \quad \frac{E(x)}{n^2} = \frac{\mu}{n^2} = \frac{n\pi}{n^2} = \frac{\pi}{n}$$

which are identical to the previous results obtained from the binomial distribution, assuming π is small.

Using the Poisson distribution and assuming $\pi = .02$ (EXPMR = 20), Table 1 reports the computed probabilities of observing x deaths for three different sample sizes (n = 100, n

= 500, and n = 2,000). Note that x by its very nature is *discrete*, and thus OBPMR is "lumpy," especially for n = 100. Indeed for that small sample size, we are as likely (P =.2707) to obtain an OBPMR that is one half the actual value of EXPMR, as we are the actual value. And there is better than one chance in ten (P = .1353) that we will find OBPMR to be zero. The situation is improved, but still disarming, with n = 500, where it is approximately equiprobable ($.0948 \leqslant P \leqslant .1251$) that OBPMR will be 14, 16, 18, 20, 22, or 24 when EXPMR is actually 20. With nearly one half of California's maternity hospitals having fewer than 500 births annually, using OBPMR for a single year is clearly a hazardous venture. However, for larger hospitals (or for several years of pooled small hospital data) the situation is improved considerably as demonstrated for n = 2,000. By summing all the P(x)'s between the OBPMR's of 14.5 and 25.5, we find that there is a greater than 90 percent chance that an OBPMR between 15 and 25 will be observed.

To simulate the behavior of OBPMR over a ten-year period for the above three sample sizes, the normal approximation to the binomial distribution is employed for large n:

$$f(x) = \frac{1}{\sigma\sqrt{2\pi}} e^{-(x-\mu)^2/2\sigma^2}$$

where

$$\mu = E(x) = n\pi$$

and

$$\sigma = \sqrt{VAR(x)} = \sqrt{n\pi(1-\pi)}.$$

These simulations are reported in Figures 3-5. A random number x is generated according to the normal frequency distribution holding EXPMR constant at 20, then an OBPMR is computed from x. It is important to note that an entirely different sequence would occur if a second simulation were to be performed. As expected, the pattern of OBPMR for n = 100 is extremely erratic in spite of the constant EXPMR, ranging from 0 to 45 per 1000. However, the ten-year mean of 18.7 corresponding to a sample size of 1000 births is reasonably close to the actual value. Note also from Table 1 that the theoretical variance of OBPMR for n = 100 is 14.1, and the sample value in Figure 3 is in close agreement at 14.7. A considerable, but reduced degree of fluctuation in OBPMR still occurs in Figure 4 for $n = 500$. In addition to the random fluctuation, another potential hazard of small sample size is revealed by the 1974-1977 segment of Figure 4, where an apparently continuous decline in OBPMR takes place. That is, if only the years 1974-1977 had been available, the unwary analyst might erroneously conclude that a major decline in OBPMR was taking place. However, the ten-year average (19.5) once again lies close to the actual value of 20 per 1000. Finally, in Figure 5 with $n = 2000$, we see that the OBPMR almost always provides a good estimate of the true probability of death.

These elementary statistical principles serve to underscore the hazards of using crude mortality rates as indicators of health care even when the risk of newborn death is held perfectly constant. In reality, of course, newborn risk profiles vary a great deal, as indicated in Figures 1 and 2. Hospitals serving disadvantaged populations and/or minority ethnic groups can have EXPMR's that are two or more times that of those serving more affluent populations. We therefore re-examine the risk component.

C. Indirect Standardization

In the previous section we assumed that the π (or EXPMR) was constant for each newborn across all UO's. Let us now relax that assumption and assume that π varies for each newborn but can be predicted, given each baby's birth weight, sex, race, and multiplicity.* For the j-th newborn born in the i-th UO, let π_{ij} be the expected probability of perinatal death based on statewide reference standards; with the j-th newborn falling into one of 380 cells. Then, for the i-th UO, the *average* expected probability of death is

$$\pi_i = \sum_j \frac{\pi_{ij}}{n_i}.$$

For example, if the UO is a hospital, we sum the individual EXPMR's for all babies born in the i-th hospital to obtain

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*Note that gestational age is not used as a predictor for several reasons: (1) as shown in Figure 1 there is more variation in perinatal mortality by birth weight than by gestational age; (2) from 15 to 18 percent of all gestations were unknown during the sample period; (3) in order to generate precise reference rates by both birth weight and gestational age, it is necessary to pool several years of cohort data together, thus creating a questionable standard on a yearly basis; and (4) no substantive differences were observed in the numerical results when gestational age was dropped from the list of predictors.

$$EXPMR_i = \sum_j \frac{EXPMR_{ij}}{n_i}.$$

(Note again that $EXPMR_{ij} = 1000 \cdot \pi_{ij}$ i.e., the former is a rate per 1000, while the latter is a probability). Next, we sum all the observed perinatal deaths (x_i) in the i-th hospital having n_i births (or N_i in 1000's) to obtain

$$OBPMR_i = \frac{x_i}{N_i}.$$

We then define as an index of the effectiveness of perinatal care within the i-th UO the Indirectly Standardized Perinatal Mortality Ratio:

$$ISPMR_i = 100 \times \frac{OBPMR_i}{EXPMR_i}.$$

If n_i is large enough to ignore the sampling component discussed in the previous section, then $EXPMR_i$ can be taken as a measure of the risk component and $ISPMR_i$ as reflective of the care component. If $ISPMR_i$ is less than 100, then the observed mortality is lower than that expected and more effective perinatal care is indicated; conversely if $ISPMR_i$ is greater than 100 then less effective perinatal care is suggested. For example, $ISPMR_i = 110$ would indicate that, ignoring statistical error, the i-th hospital had a perinatal mortality rate that was 10 percent higher than the statewide average after accounting for the risk profile of each of its newborns.

However, as we have seen, except for the case of very large UO's, the sampling component usually cannot be ignored. That is, ISPMR has a sampling variance that must be accounted for. It can be shown that

$$VAR\ (ISPMR_i) = \frac{VAR\ (OBPMR_i)}{EXPMR_i^2}$$

or in probabilities

$$VAR\ (ISPMR_i) = \frac{\sum_j \pi_{ij}(1-\pi_{ij})}{(\sum_j \pi_{ij})^2}$$

Once this value is found, then one can compute the standard normal test statistic for large n:

$$Z_i = \frac{(ISPMR_i - 100)}{\sqrt{VAR\ (ISPMR_i)}}.$$

This quantity can then be used to test the null hypothesis that $ISPMR_i = 100$; i.e., that the care component for the i-th UO is average. If the absolute value of Z_i is 1.96 or greater, then $ISPMR_i$ is judged to differ from the normative value of 100 in a statistically significant sense ($P < .05$). Depending on the situation and at the discretion of the analyst, absolute values of Z_i smaller than 1.96 may be judged to be statistically significant.

When a Z_i suggests a significant $ISPMR_i$ a modified value of $ISPMR_i$ is computed so as to minimize the effect of the sampling component. This is accomplished by means of a Bayesian procedure [4] which adjusts each $ISPMR_i$ toward the average level of 100 in proportion to the unreliability of the measurement. As discussed above, UO's with many births will have relatively small sampling errors for OBPMR and will be subjected to small adjustments for ISPMR. Conversely, when there are fewer births the chance for sampling error is large, and potentially large adjustments can occur. The resultant index, which can be thought of as a more representative ISPMR, is referred to as the Bayesian Standardized Perinatal Mortality Rate (BSPMR), and is defined as

$$BSPMR_i = \frac{\left[\dfrac{ISPMR_i}{VAR\ (ISPMR_i)} + \dfrac{100}{VAR\ (ISPMR)}\right]}{\left[\dfrac{1}{VAR\ (ISPMR_i)} + \dfrac{1}{VAR\ (ISPMR)}\right]}$$

where VAR $(ISPMR_i)$ = sample variance of $ISPMR_i$ (see above) and VAR $(ISPMR)$ = intrinsic variance of all $ISPMR$ over all units of observation. As the uncertainty in measurement of $ISPMR_i$ increases due to small sample sizes, the relative importance of $ISPMR_i$ diminishes relative to the norm of 100, and the resultant $BSPMR_i$ lies closer to the normative value. This procedure will minimize the sum of expected squared errors for all UO's combined.

The methodology developed relative to perinatal mortality can, of course, also be applied to its fetal and neonatal components. There are two major reasons for reporting the separate components. First, there is some question as to the efficacy of perinatal care in preventing what may be unsalvageable fetal deaths, whereas live births may lend themselves more to medical management. Second, although perhaps too simplistic, the fetal death rate may largely reflect obstetric practice, while the neonatal death rate may be tied more closely to neonatal intensive care. Of course, there are numerous hazards to this interpretation. Nonetheless, it is advisable to compute all three adjusted rates and to examine them simultaneously when making decisions concerning the relative effectiveness of perinatal care. The notation used for the fetal and neonatal components parallels that for perinatal mortality, e.g., EXFMR and EXNMR in place of EXPMR, OBFMR and OBNMR in place of OBPMR, etc.

It is appropriate to summarize the methodological approach at this point. The accumulated evidence points to a complicated array of factors that affect fetal well-being, the result of which influences fetal growth rates and thus birth weight. Moreover, birth weight is by far the most important predictor of survival. The approach taken here is to attempt to measure differences in perinatal mortality for given levels of birth weight and three newborn factors: ethnicity, sex, and multiplicity. By comparing the observed and expected rates and making the appropriate statistical adjustments, we attempt to measure the effectiveness of health care during the intra- and postpartum (i.e., perinatal) period. By taking birth weight as given, we cannot measure the contribution of prenatal care to fetal and newborn well-being. Although it is hoped that similar methodologies can ultimately be applied to the latter problem, we are constrained at present to measure maternal variables which are, at best, crude indicators of the risk of low birth weight.

D. Description of Variables

A description of the 31 variables selected from the MCHDB is contained in Table 2. With few exceptions, the variables are defined in percentage terms. The variable BIRTH was defined as the total number of live births and fetal deaths minus the number of births having weights less than 501 g and the number of unknown birth weights. The less than 501 g criterion was applied out of consideration of the definition of a fetal death as a product of conception of 20 weeks or more gestation. Although the Department of Health Services excludes births of less than 20 weeks from the linked record file, it cannot apply this criterion when gestational age is unknown. And because gestational age is often unreported for such very small fetuses, there remain a residual number of fetal deaths in the file that are in reality less than 20 weeks gestation. Also, with the increased number of induced abortions occurring in the 1970's, there is an increased possibility of classifying some planned abortions as live births. In Figure 1 we observe the 50th percentile to fall at about 500 g at 22 weeks. Further, the likelihood of survival below 500 g is exceedingly small, and effectively zero. These facts, coupled with our interest in measuring the effectiveness in preventing deaths among fetuses who have at least a slim chance of survival, prompted us to remove from the file all births having birth weights of less than 501 g. Similarly, because many of the unreported birth weights are for small fetuses who are likely to be stillborn or die shortly thereafter, the unknown birth weights are also removed. Fortunately, birth weight in California is well reported (99.8 percent) so that these edits reduced the file by a very small percentage. Finally, we tested the behavior of the outcome variables by including and excluding both the < 501 g and unknown birth weight records, and found no substantive differences in the behavior of the indexes. Indeed, the exclusion of the very small fetuses appeared to enhance the sensitivity of the effectiveness indexes.

The remaining variables in Table 2 fall into several groups. First, is the ethnicity group composed of California's three major races: white non-Spanish, white Spanish-surname, and black. A residual ethnic class, labelled "other" is also defined. Next are the crude indicators of socioeconomic status: no reported prenatal care (either reported as "none" or "unknown"); out-of-wedlock status as inferred primarily by a set of rules for comparing surnames of parents and child [5]; and short interpregnancy intervals (< 17 months) [6]. These variables were defined and selected as potential predictors of low birth weight, hence high expected death rates. With perhaps the exception of PARA1, variables from the next group, measuring age-parity combinations, were also chosen as maternal risk indicators. Two extremes of the age distribution were defined as well as two extremes in the number of previous births and the combination of low parity and older age. Because multiple pregnancies constitute a classic example of intrauterine growth retardation and hence low birth weight, the percentage multiple pregnancies was also chosen. Of course, it was realized that the incidence of multiple births is likely to be uniformly distributed.

Thus, with the exception of variables 2, 5, and 11, the variables 2-14 are crude indicators of the risk of low birth weight, which is measured by variable 15, the percent of births weighing less than 2501 g. Because of the current debate concerning the increased numbber of obstetric interventions, the percent cesarean sections is also included. Finally, we have the unadjusted and adjusted mortality variables which have been described earlier.

E. Limitations and Caveats

The methodology described above was designed to improve the validity of perinatal mortality rates as indicators of the efficacy of obstetric and newborn care within a particular unit of observation. While we believe that the results represent a substantive improvement over previously available natality/mortality statistics, there nevertheless exist a number of limitations and qualifications. For this reason the results should not be viewed in absolute terms, but should be considered as guideposts to be used in conjunction with other information; e.g., structure and process data resulting from licensing and certification activities. At present, there are three major limitations on the information contained in the MCHDB: (1) limitations related to the completeness, accuracy and timeliness of linked vital record information; (2) limitations resulting from the geographical movements of mothers and newborns; (3) fundamental statistical limitations on the method of indirect standardization.

Limitations of the vital record information can be described in terms of completeness of registration, quality control procedures, completeness of birth-death match, infants lost to followup, and classification by ethnicity [7].

The registration of live births and infant deaths in California is thought to be nearly complete for births occurring in the State. Fetal deaths, however, are thought to be underregistered. Through a cooperative exchange program between the states, reallocation of birth, death and fetal death certificates to the state of residence has been virtually complete since 1955. Records of vital events occurring in foreign countries are not reallocated, however, which may create a problem in California due to the substantial population that flows across the California-Mexico border. In matching birth and death records the following registration errors are sometimes uncovered: (1) failure to file a birth certificate; (2) filing the wrong certificate; and (3) filing duplicate certificates. However, these types of registration irregularities are minimal and are usually corrected in the record matching process.

Quality control problems are potentially a more serious limitation on the validity of the vital record data. Errors in coding and keypunching hundreds of thousands of records undoubtedly occur. Samples of processed records are reviewed to detect systematic errors, and it has been found that error rates are quite low. If a systematic error is uncovered, a correction procedure is applied. Perhaps the most serious quality control problem with respect to the MCHDB is the identification of the hospital of birth from the birth certificate. Because the subset of hospitals which offer obstetric and newborn care is constantly changing, and because hospitals frequently change their names or addresses, the hospital of birth as written on the birth certificate may sometimes be unrecognizable. If so, no numerical identifying code can be assigned to that hospital and the birth must be allocated to an "unknown" hospital category within the county of birth. While most of these unknowns originate in small clinics, physicians' offices, or in new hospitals, they occasionaly can be the result of a name or address change. In the latter case a discontinuity in the historical record for a particular hospital will occur.

After the birth-death match is completed, 1-2 percent of the infant death records remain unmatched. Records for these unmatched cases are created by inserting "not reported" codes for the missing birth certificate information. This small number of synthetic records are not expected to have a significant bias on the results.

The converse case of missing death certificates or "infants lost to followup" poses a more serious problem since there is little in the way of tangible evidence of their existence. The two major causes of missing death records are: underregistration of infant deaths and deaths to infants following migration from the U.S. Although the extent of this problem is unknown, it is likely to be more acute among the Hispanic subpopulation due to population movements across the California-Mexico border. The net result would thus be a tendency to understate mortality rates for Hispanics.

Information on race of mother and father is required on birth and fetal death certificates. Unknown races and those entered as "Mexican" are classified as "white". Race of the child is generated by comparing the two parents' races; e.g., if one parent is white and the other nonwhite, the child's race is coded to be the same as the nonwhite parent; if either parent is black, the child's race is coded as black; if neither parent is white or black, and the parents' races are different, then the child is assigned the father's race. In addition to the race classification, a Spanish surname coding is employed using a computer program based on the root ending of names [8]. This allows the white subpopulation to be further divided into "white Spanish" or "white non-Spanish".

In spite of the above limitations and qualifications, the linked birth-death cohort files have the distinct advantage of facilitating a large scale population-based monitoring of the health of mothers and infants. Because birth and death records are essential for the proper functioning of modern society, the added costs of creating the cohort files from these records is marginally small. The birth registration system therefore provides a low-cost and effective means of health care surveillance over wide geographical regions at different points in time. With respect to timeliness, however, there is yet another limitation as the sheer size of the files requires a considerable amount of time for careful processing. And because of the cohort nature of the files, full processing does not usually begin until the end of the calendar year. Indeed, since infant deaths are defined as deaths to live born infants up to one year following birth, the birth-death cohort is not completed until one full year after the end of the birth cohort calendar year. These delays presently combine to produce a 2-3 year lag between the end of the cohort year and the availability of computerized linked record data. While efforts are underway to minimize this delay, they are hampered by changes in the form of the birth certificate as well as cutbacks in available resources. It is hoped that eventually linked record information as it relates to perinatal mortality will be available within one year of the end of the cohort year, thereby making the data more useful for policy purposes.

Because the MCHDB has hospital of birth as its smallest UO, the higher levels of aggregation, e.g., city, county, or HSA, intrinsically report events by place of occurrence. Moreover, since death records are traced back to the birth certificate, all deaths are attributed to the hospital of birth. This procedure seems reasonable in spite of infant transport activities since hospitals that have excellent infant transport programs should have proportionately fewer deaths. In the case of maternal transport and referral, however, the situation is not so clear. While ideally the effectiveness of perinatal care should be measured on a place of occurrence basis, such may not be the case for the maternal risk indicators. Because the latter may be useful for public health planning, e.g., pinpointing the geographical source of a high proportion of adolescent pregnancies, it may be desirable to compute them by place of residence. In short, when we observe a high EXPMR in a certain region, we are unsure as to the ultimate geographical source.

Some light can be shed on this problem by inspecting the 1977 birth cohort according to county of residence versus occurrence as shown in Table 3. The Net Flow of Births (NFB) *into* a county is defined as:

NFB = births by occurrence - births by residence.

When NFB is positive, the county is a net "importer" of births, and when NFB is negative, it is a net "exporter" of births. Obviously, this information is useful when interpreting the MCHDB data, especially with respect to programs aimed at regionalizing perinatal care. It comes as no surprise that all of the counties having large positive NFB's are urbanized and many of those having negative NFB'S are rural, since a major objective of regionalization is to refer high-risk women to secondary and tertiary perinatal centers. Nonetheless, some of the largest negative NFB's are from urbanized counties that are adjacent to other urbanized counties, thus complicating the epidemiology of obstetric risk.

It is useful, therefore, to define two additional indexes: the Residence Index (RI), defined as

$$RI_i = 100\times \frac{Births\ i-th\ County's\ Residents\ Occurring\ in\ i-th\ County}{Total\ Births\ i-th\ County's\ Residents}$$

and the Occurrence Index (OI), defined as

$$OI_i = 100\times \frac{Births\ i-th\ County's\ Residents\ Occurring\ in\ i-th\ County}{Total\ Births\ Occurring\ in\ i-th\ County}$$

An RI_i near 100 indicates that most residents deliver in their "own" county, while a low value indicates that they deliver elsewhere. An OI_i close to 100 reveals that most births occurring in a particular county are to the residents of that county, whereas a low value shows that many births are to residents from outside the county. A county with major referral centers having a medium-sized population, e.g., San Francisco, will have a high value for RI and a low value for OI. Conversely, many rural counties, whose residents travel to urban areas to deliver, will have a low value for RI and a high value for OI. For counties having a large flux of obstetric patients, both in and out, such as San Bernardino, *both* the RI and OI will be considerably less than 100.

Obviously, it is important to account for NFB, RI, and OI when using the MCHDB information for planning purposes. Although it is desirable to examine the flows of both mothers and infants using smaller geographic regions, that requisite information is not yet available by means of birth and death certificates. This limitation may be improved somewhat in the future through the addition of zip codes to the linked cohort files.

Added to the above limitations and qualifications on the matched vital record data is the fundamental limitation on the standardization procedure. That is, we have assumed that a multitude of maternal factors combine to produce newborns of varying degrees of viability, measured primarily by birth weight. Then, given the level of newborn risk at the time of birth, we attempt to measure how different units of observation compare with each other in reducing the actual perinatal mortality rate. It is important to note that the maternal risk variables described in Table 2 are *not* used in the risk adjustment procedure, but are reported to assist planners in uncovering the source(s) of newborn risk. It should be clear, therefore, that the ISPMR index does not account for the contribution of preventive care in reducing the risk of low birth weight. Of course, it would be desirable to use maternal risk factors only in the adjustment procedure so as to account for both the prenatal as well as the intra- and postpartum components of perinatal care. This fundamental limitation on the standardization process is the result of inadequate data on maternal risk factors on a widespread basis, and to an incomplete understanding of the etiology of prematurity and low birth weight. While these constraints on the technique will undoubtedly be relaxed in the future, the ISPMR and BSPMR indexes are presently capable of evaluating *only* the intra- and postpartum components of obstetric and newborn care.

III. RESULTS

A. Statewide Trends

Statewide values for the 31 selected MCHDB variables for the 1970 through 1977 birth cohorts are reported in Table 4. State total for all years are also reported. These figures represent baseline values to be used for comparison purposes with other smaller UO's. A number of trends are readily apparent. There has been a decrease in the number of hospitals reporting at least one birth (NHOSP) over the eight-year period from 435 in 1970 to 405 in 1977. The eight-year total of 503 is not inconsistent with these results since some hospitals have closed their obstetric units while new hospitals come into existence. The net decrease of hospitals reporting at least one birth may, however, be reflective of efforts aimed at the regionalization of perinatal care. In general, NHOSP tends to overestimate the number of hospitals actually involved in obstetric and newborn services since emergency births sometimes occur in hospitals and clinics not having formal obstetric services. The number of births (BIRTH), on the other hand, shows no clear trend, but appears to be "U-shaped," with the minimum occurring in 1973.

A shift in the relative proportions of births by ethnicity is very apparent, with a rapidly increasing proportion of white Spanish (SPAN) and a decreasing proportion of white non-Spanish (WHITE) births. Somewhat smaller increases are noted in the "other" category, with a slight increase in the proportion of blacks. The proportion of mothers having no reported prenatal care (NOPRE) follows an erratic, but somewhat increasing pattern. A substantial increase in the inferred proportion of out-of-wedlock (OUTWED) births is noted; however it should be emphasized that the inferential nature of this variable depends in large part on traditional conventions regarding the parents' and child's surname [5], and rapidly changing marital arrangements may therefore threaten to limit the validity of this variable to an unknown degree. A significant decrease in the proportions of short interpregnancy intervals is noted (SHORT), although this trend seems to have leveled out in recent years.

In spite of widespread contemporary concern over teenage pregnancies, there does not appear to be an increasing trend in the proportion of births to females less than 18 years old (TEEN). Indeed, the rate was lower in 1977 than 1970, and smaller in 1977 than the eight-year average. The percentage of births to women 35 or older (OLDER), however, shows a definite downward trend, as does the proportion of grand multiparas (PARA6). The latter two observations are suggestive of an increased incidence of family planning and a trend toward smaller family sizes. Concurrent with the decrease in the proportion of grand multiparas has been an increase in the percentage of primiparas (PARA1), as well as in the percentage of older primiparas (OPARA1). The latter trend may simply be related to the increased proportion of primiparas, but could also be reflective of the rising proportion of women who have not yet had any children [9]. Finally, as is to be expected, there is no apparent trend in the proportion of multiples (MULT), averaging about two percent of all births, or about one percent of all pregnancies.

As has been discussed earlier, the aforementioned variables are but a few of many maternal risk indicators that interact in as yet incompletely understood ways to influence the fetal environment and hence birth weight. Secular trends for some of these variables, such as WHITE, SPAN, BLACK, NOPRE, OUTWED, and OPAR1 tend toward increased maternal risk, while others, such as SHORT, OLDER, and PARA6 are suggestive of movement toward lower degrees of risk. It is not surprising, therefore, to see a somewhat ambiguous trend in the proportion of low birth weight deliveries (LOBW). Yet the overall trend is negative, indicating an improvement in fetal health in the State of California during the decade of the 1970's.

Turning to the second group of variables in Table 4, as described elsewhere [2,10], there has been a rapid increase in the proportion of cesarean deliveries (CSEC) during the 1970's. While the reason for the increase is not totally understood, at least four major influences have been noted: (1) the advent of electronic fetal monitoring; (2) the increased access of premature infants to neonatal intensive care; (3) the change of indications for the use of cesarean section; and (4) the changing medicolegal climate. As shown in Table 4, the statewide cesarean section rate (CSEC) has been increasing very rapidly, more than doubling from 6.9 percent in

1970 to 15.4 percent in 1977. However, the OBPMR has been declining during the same period, falling from 21.3 per 1000 in 1970 to 14.2 per 1000 in 1977. Using hospital-specific data for the 1977 cohort, a statistically significant negative correlation was observed between CSEC and ISPMR. This and other results suggested that hospitals having higher rates of intervention in obstetrics have lower risk adjusted perinatal mortality rates [2]. Of course, this finding does not prove that cesarean section is beneficial to perinatal outcome, but it may nevertheless serve as a proxy indicator of technological sophistication. On the other hand, a high CSEC value may reflect an above-average degree of unwarranted surgery, hence the variable must be interpreted with caution.

The remaining variables in the lower half of Table 4 are related to the indirect standardization process as discusssed above. By definition, EXPMR must be exactly equal to OBPMR when these two variables are computed for the entire state since the expected rates are based on the statewide experience for a single year. It follows, then, that ISPMR and BSPMR must both equal 100, hence ZPMR must be zero. The same holds true for the fetal and neonatal components of perinatal mortality; i.e., EXFMR, OBFMR, . . ., EXNMR, OBNMR, etc. Therefore, the only nonredundant information in the lower half of Table 4 is contained in CSEC, OBFMR, OBNMR, and OBPMR. The remaining values will, of course, have nontrivial values for smaller UO's; e.g., HSA's, counties and hospitals.

At the beginning of the decade the neonatal component of perinatal mortality was larger than the fetal component, with OBNMR = 11.4 and OBFMR = 10.0. As the decade progressed, however, the neonatal rate declined faster than the fetal rate, crossing over in 1974, and plummeting to 6.8 per 1000 by 1977, with the fetal rate dropping to 7.5 per 1000. The sources of this disparity are uncertain; perhaps it reflects the advent of neonatal intensive care, infant transport systems, etc., having a greater impact on neonatal mortality, or it may be indicative of a larger proportion of "unpreventable" fetal deaths. In any event, it is abundantly clear that there is a significant downward trend in perinatal mortality and its components, which should be accounted for when making comparisons of perinatal outcomes.

B. By HSA

Average values for the 31 MCHDB variables over the entire eight-year sample period are reported for California's 14 Health System Agencies (HSA's) in Table 5. The top row of figures, corresponding to "HSA-0," is identical to the bottom row of figures in Table 4, and thus reflects the statewide averages for the sample period. Values for each variable for the 14 HSA's can thus be readily compared to their statewide norms.

To facilitate the discussion that follows, a single HSA (HSA-5) is chosen as an example. Compared to the remaining 13 HSA's, HSA-5 is noticeably above average for: BLACK, OUTWED, LOBW, CSEC, EXNMR, and EXPMR. And it appears to be below average for: SPAN, SHORT, OLDER, PARA6, BSFMR, BSNMR, and BSPMR. The cause for the above-average newborn risk indexes (LOBW, EXNMR, and EXPMR) is not clear since some of the maternal risk indicators are above average while others are lower than average. Because ZPMR = -2.84 for HSA-5, reference to a standard normal distribution reveals it extremely unlikely ($P < .005$) that the "true" ISPMR for HSA-5 is equal to 100. Indeed, our "best guess" at ISPMR after accounting for sampling error is BSPMR = 96.3, which differs little from ISPMR = 96.0 due to the large sample of 181,494 births. We conclude, therefore, that the risk-adjusted perinatal mortality rate in HSA-5 is 3.7 percent below the state average. Inspection of the fetal and neonatal components reveals a significantly lower value for ISFMR compared to ISNMR in HSA-5, with the adjusted fetal rate estimated to be 7.0 percent below the state average, while the adjusted neonatal rate is -2.6 percent.

Values for the outcome variables for HSA-5 may be summarized as follows: the expected perinatal mortality rate is significantly higher than the state average, with the observed rate approximately equal to the statewide value, thus yielding a significantly below-average risk-adjusted perinatal mortality rate. In short, HSA-5 is characterized by above-average newborn risk, but below-average mortality for a given level of risk. Scanning Table 5 we see that HSA-1 is a polar case with below-average newborn risk, but an above-average adjusted mortality rate. Both HSA-5 and HSA-1, however, have observed mortality rates that are nearly equal to the state average. These results have obvious implications regarding the allocation of health resources: it appears that prevention of low birth weight should be stressed in HSA-5, while the improvement of intra- and postpartum care demands attention in HSA-1.

Other HSA's also show imbalances. For example, HSA-9 has an exceedingly high ISPMR, with the standardized perinatal mortality rate estimated at 10 percent above the state average. HSA-4 displays an above-average EXPMR but a below-average ISPMR. HSA-11 has the highest EXPMR and a moderately high ISPMR, yielding one of the highest HSA-specific OBPMR's: this result is of much concern since HSA-11 (Los Angeles County) has by far the largest population in the state.

Yearly values for the MCHDB variables are reported in Table 6 for the example HSA. Briefly summarized, HSA-5 is characterized by a decreasing proportion of white non-Spanish births, increasing proportions of black and other ethnicities. Unusually high values for NOPRE are observed in 1974 and 1975. Values for the other variables tend to follow the statewide trends in Table 4, but may be displaced in absolute terms as summarized in Table 5. A similar table for the specific HSA addressed in this report is included in the Appendix.

C. By County

Data within HSA-5 are reported by county of occurrence in Table 7. By simple inspection it is apparent that Alameda and Contra Costa counties display some marked differences. The former has about twice as many hospitals and almost three times the number of births. Further, the declining white non-Spanish and increasing black subpopulations within HSA-5 are seen to be centered in Alameda County. The excursions in the LOPRE variable for 1974 and 1975* as well as the high percentage of out-of-wedlock births can also be traced to Alameda County. Consistent with these differentials is the higher percent of low birth weights and the higher expected mortality rates in Alameda County. The differential in observed mortality rates is ameliorated, however, by significantly lower standardized mortality ratios therein.

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*This result may possibly be an artifact caused by incomplete reporting since LOPRE is computed from the sum of births having prenatal care reported as "none" and reported as "unknown."

As will be described in Section III.E., the row labeled "PRCNTL" reports the percentile ranking of each variable for a particular county relative to all counties in California. We see, for example, that Alameda County ranks above the 90th percentile for the variables NHOSP, BLACK, OUTWED, OPARA1, LOBW, EXFMR, EXNMR, and EXPMR.

In summary, a higher degree of maternal risk in Alameda County seems to have resulted in an increased level of newborn risk, which was offset somewhat by more effective intra- and postpartum care. Thus, the resulting observed perinatal death rate was only 1.4 per 1000 higher in Alameda compared with Contra Costa County.

Corresponding data for HSA-5 by mother's county of *residence* is presented in Table 8. As explained earlier, these data may be useful in tracing geographical concentrations of high maternal risk. The interpretation of the perinatal outcome indexes by residence is less valid, however, since they are not based on aggregations starting at the locus of delivery of health care services. That is, the outcome indexes by residence measure perinatal outcomes to infants born to all mothers residing in a particular county regardless of where the delivery takes place. Thus, the effectiveness of care indexes cannot be attributed to a particular institution in which the delivery occurred. The expected mortality rates by residence do, however, have a valid interpretation; viz., they are measures of maternal risk within a particular geographic region. When EXPMR differs in Table 7 versus Table 8, it may therefore be possible in conjunction with Table 3 to discern the direction of flow for high risk patients.

For example, from Table 3 we see there is a net flow of patients into Alameda County and out of Contra Costa County. Much of this flow is, of course, between these two adjacent counties. Comparison of the maternal risk variables in Tables 7 and 8 suggests that the flow from Contra Costa County to Alameda in 1977 was predominately black patients with above-average risk. The net result for that year was to increase the expected mortality rates in Alameda County when the data are tabulated by occurrence vs. residence, and conversely, to decrease the expected mortality rates in Contra Costa County for occurrence compared to residence.

Again, similar data is reported in the Appendix for the specific HSA that is the subject of this report. We leave it to the reader, who is more likely to be familiar with details regarding that HSA, to interpret the county-specific data by referring to the examples discussed here.

D. By Health Facility Planning Areas

MCHDB data tabulated according to Health Facility Planning Areas (HFPA's) within HSA-5 are reported in Table 9. These geographic regions tend to be city-oriented and thus represent finer subdivisions than do counties. The data were generated by aggregating over the hospital of occurrence within individual HFPA's. HFPA boundaries were determined according to a listing published by the Office of Statewide Health Planning and Development, dated January 1, 1979. Because federally-owned hospitals do not come under the jurisdiction of state or local planning authorities, they have been assigned an HFPA number according to the county within which the facility is located. It is also of interest to monitor the non-hospital births within counties, so that they have also been assigned an HFPA number.

In Table 9, HFPA-411 and 413 describe information from non-federal hospitals in Contra Costa County, followed by HFPA-415, 417, 419 and 421 in Alameda County. In Contra Costa County HFPA-411 and 413 are quite disparate, the former being predominately white by ethnicity, while the latter has more than 50 percent minority subpopulations. These ethnic differences are manifested in higher values for the maternal risk variables in HFPA-413, resulting in a significantly larger percentage of low birth weights and higher expected mortality rates. Nor does the effectiveness of perinatal care appear to be as high in HFPA-413 compared with 411; the latter appears approximately average in effectiveness, whereas the former has a standardized perinatal mortality ratio between 3 and 5 percent above average. It appears that this above-average standardized perinatal mortality in HFPA-411 stems from the neonatal component. The disparity in the cesarean section rates for these two HFPA's is also noteworthy.

Large differentials in ethnicity are also apparent in Alameda County, with HFPA-415 and 417 having a high percentage of minority births, and HFPA-419 and 421 predominantly white non-Spanish. Again, high values for some of the maternal risk variables apparently cause

HFPA-415 and 417 to have a higher percent of low birth weights as well as higher expected mortality rates. In terms of effectiveness, however, HFPA-415 and 417 perform quite well, with standardized mortality ratios from 5 to 10 percent below average. HFPA-421 also has below-average adjusted perinatal rates, but HFPA-419, comprised of only one hospital, is slightly above average. The latter result appears to stem from an above-average neonatal component.

HSA-5 contains only one federally-owned hospital, located in Alameda County, labelled HFPA-200 in Table 9.[*] The obstetric profile for this hospital differs from the average non-federal California facility in a number of anticipated ways. In terms of age-parity factors, we find low percentages of older and adolescent mothers and those of high parity, but a large proportion of primiparas. Proportions of mothers having no reported prenatal care, those bearing children out-of-wedlock, and having short interpregnancy intervals are lower than the statewide averages. The percentage Spanish surname mothers is also lower than average with the proportion of white non-Spanish and other ethnicities above average. In spite of the prevalence of low-risk indicators, the percentage low birth weight and the expected mortality rates are greater than the statewide means. One can only conjecture as to the unmeasured element of risk: perhaps it is the high mobility associated with military life, perhaps wives of military personnel are more likely to smoke, etc. In terms of effectiveness of care, this federal hospital appears to have an adjusted perinatal mortality rate that is slightly above average, a result that, like other HFPA's within HSA-5, appears to stem from the neonatal component.

Nonhospital births are tabulated by county in Table 9 as HFPA-8001 for Alameda and HFPA-8007 for Contra Costa, the last digit indicating the alphabetical ranking of the county in the state total of 58. The data for these units of observations are of interest because of the increased numbers of births in recent years, presumably as a result of the home birth movement. Absolute numbers of births in nonhospital settings in HSA-5 have more than doubled, increasing from 93 in 1970 to 223 in 1977. During this rising trend, however, there is evidence of substantive changes in the maternal and newborn risk characteristics. The source of these changes is no doubt an increased proportion of planned home deliveries among the nonhospital group. The tendency toward lower risk is reflected by the rapidly declining proportion of low birth weight deliveries and the lower expected perinatal mortality rates, although small numbers of births produce erratic patterns. At the beginning of the decade, the standardized mortality ratio for nonhospital births in HSA-5 was significantly larger than average, but by 1977 the ratio stood at or slightly below the statewide norm. It would appear from these results that the increase in nonhospital births in HSA-5 should not be cause for alarm. These results are consistent with statewide trends for nonhospital births (see Sec. III.F.4).

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[*] Often, as is the case here, a county may contain only one federal facility. In that case, identical data will occur in the hospital specific data corresponding to that facility, with the exception of the Bayesian indexes. This apparent disparity stems from the estimate of the "intrinsic" variance in the standardized rates across UO's, which will be smaller for UO's that are inherently larger. In the case of HFPA's containing only one federal hospital, it is therefore more realistic to use the hospital specific Bayesian ratios. Note also that the percentile ranking for the NHOSP variable is not reported on an HFPA-specific basis since many HFPA's have only one or two hospitals, thus resulting in many ties in the ranking.

As before, similar data for the HSA to which the report is addressed is contained in the Appendix.

E. By Hospital

1. Overview

The fundamental unit of observation, around which the MCHDB is organized, is the individual hospital. It is important to note that the linking process developed by the Department of Health Services assigns all infant deaths to hospitals on the basis of place of birth. Thus if an infant is transported to a referral center postpartum and subsequently dies, the matched birth-death record is identified by the hospital of birth. Although the ideal method to account for infant transfers between hospitals presents a number of problems, it is thought that this procedure is a reasonable first approximation to measuring effectiveness of intra- and postpartum care. Hospitals having well-developed programs of infant transport should fare better under such a protocol than those that do not.

Hospitals for the HSA addressed in this report are listed in the Appendix alphabetically by name within the county they are located. Note that all hospitals recording at least one birth during the 1970-77 period are listed, regardless of size or type of service. Obviously, some of these do not routinely provide obstetric services, and are of little importance in the planning of maternal and infant health services. Others may exhibit a rapidly declining number of births, converging toward zero, thus indicating that they have dropped their obstetric services. Occasionally a hospital may have no observations for earlier years, then exhibit an increasing trend in the number of births; this pattern, of course, is indicative of a hospital just beginning to offer obstetric services. On rare occasions, a single year or several years may be missing from an otherwise continuous sequence. This phenomenon can probably be attributed to a name and/or address change which caused the hospital to be unidentifiable on birth records over a period of time. These vaguaries, coupled with the elementary statistical limitations discussed earlier, strongly suggest that statistics for individual years must be viewed with some skepticism, and we should place more emphasis on totals over several years or look for trends over time.

Potential hazards involved in using year-to-year observations as well as guidelines for interpreting the hospital-specific data are demonstrated in Figures 6-9. Figure 6 is a plot of OBPMR for four different UO's: the entire state (~ 328,000 mean annual births), HSA-5 (~ 22,700 mean annual births), HFPA-417 centered in the City of Oakland (~ 5,300 mean annual births), and a sample hospital (Hospital A) from HFPA-417 (~ 650 annual births). While all four UO's exhibit a declining trend in OBPMR, the pattern becomes more erratic as the annual number of births decreases. As indicated by the eight-year averages on the far right, however, it is unlikely that all the observed differences in OBPMR can be attributed to chance alone, especially for Hospital A.

Newborn risk variations across UO's and over time are plotted in Figure 7. Although there remains some erratic behavior in EXPMR, diminishing as the number of births increases, the year-to-year variation is considerably smaller than for OBPMR. Moreover, the eight-year averages for EXPMR show the same rankings as for OBPMR, with Hospital A having a high degree of risk.

Newborn risk is accounted for in Figure 8 by computing ISPMR = 100 x OBPMR/EXPMR. Again, the variation in ISPMR is inversely proportional to the number of births, with excursions for Hospital A approaching a factor of two. After risk is accounted for, the eight-year averages in Figure 8 reveal that the adjusted mortality rates for the HSA-5 UO's are *lower* than the statewide rate, not higher as suggested by OBPMR in Figure 6. That is, the higher perinatal mortality rates in HFPA-417 and Hospital A can be attributed to a higher degree of newborn risk. On a yearly basis, however, there are still large variations in ISPMR due to sampling error. Therefore, yearly observations must be interpreted with caution.

While the sampling component of ISPMR cannot be totally eliminated, its effect can be ameliorated by means of the Bayesian adjustment, as shown in Figure 9. There, we observe a reduction in the year-to-year variability of the effectiveness indexes, especially for HFPA-417 and Hospital A, where the chance of sampling error is large.

A case-by-case description of the 31 MCHDB variables on a hospital-specific basis is not practical due to the bulk of data involved: there are potentially 31 variables x 8 years x ~ 415 hospitals = ~ 103,000 entries. And if the eight-year totals are included, there are potentially ~ 116,000 numbers. Of course the actual number of hospital-specific observations is somewhat smaller since some hospitals do not have births for all years. Nonetheless, there remain in excess of 100,000 figures for evaluation. Clearly, the inspection and interpretation of a dataset of such magnitude is beyond the capability of a single individual, which is a major reason for reporting the data to other interested and qualified parties on an HSA-specific basis. Such a pluralistic utilization of the MCHDB information should allow those individuals with an immediate knowledge of community profiles and medical resources within their own geographical areas to make more meaningful decisions related to the planning of obstetric and newborn services.

Therefore, the hospital-specific results are not described in detail here. Rather, we have selected several sample hospitals from the entire MCHDB to serve as examples for illustrating proper methods for data interpretation.

2. Examples

As the first example, consider Hospital A, whose yearly values for the OBPMR, EXPMR, ISPMR, and BSPMR variables have already been described in Figures 6-9. Table 10 reports the yearly values for all 31 of the selected MCHDB variables. Compared to the statewide values reported in Table 4, Hospital A is characterized by very high percentages for BLACK, NOPRE, SHORT, OUTWED, TEEN, and PARA6. It is not surprising, therefore, to find a value for LOBW that is more than twice the statewide average. Equally unsurprising is the relatively high values for EXFMR, EXNMR, and EXPMR, which also are about double the statewide average. Hospital A thus serves as a classic case of high maternal risk factors producing a high degree of newborn risk. Its large values for the observed mortality rate, again approximately double the state average, are therefore not unexpected. Indeed, standardized ratios indicate that the risk-adjusted mortality rates are somewhat *lower than average*, bordering on the conventional threshold of statistical significance. This example underscores the hazards in using unadjusted mortality rates for single years, where the observed perinatal mortality rate for Hospital A in 1971 was more than 50 per 1000. Data from the MCHDB show, however, that most of this alarmingly high rate can be explained by the high degree of maternal risk and subsequent low birth weight.

Note that the below-average standardized ratio *does not* justify the high observed rates, since an observed rate over the eight-year period which is double the state average is definitely cause for concern. What the data *do* indicate is the apparent *source* of the high observed rate, viz. the high proportion of low birth weight infants. Given this high degree of low birth weight, chances for perinatal survival in Hospital A are somewhat better than, but not significantly different from, the average chances of newborn survival based on statewide norms. These findings do not mitigate the responsibility of Hospital A to attempt to reduce low birth weight by prenatal care and other means - this is especially true since the percentage of mothers having no reported prenatal care in Hospital A is more than five times the state average - rather, it serves to emphasize the urgency of taking measures to reduce the risk of low birth weight for many of Hospital A's patients.

It is abundantly clear that a review of the values for the 31 MCHDB variables within a particular hospital is incomplete without reference to normative standards. In the case of the standardized mortality ratios and their standard normal test statistics (ZFMR, ZNMR, and ZPMR) it is possible to refer to a table summarizing the area under a normal distribution and thence make probabilistic statements regarding the chances of observing a particular Z-value. A similar procedure could be applied to other variables as well, using the statewide average values as reported in Table 4. Implicitly, this was the process loosely followed above when discussing the values for Hospital A. For example, when it was stated that Hospital A had a high proportion of black births, the eight-year average value of 49.8 percent in Hospital A in Table 10 was seen to be five times the statewide value of 10.0 percent in Table 4. Similar comparisons between Table 10 and Table 4 also revealed above-average values in Hospital A for the variables NOPRE (14.90 vs. 2.90), SHORT (21.8 vs. 14.8), OUTWED (40.8 vs. 15.0), TEEN (12.7 vs. 6.1), PARA6 (3.14 vs. 1.78), LOBW (15.0 vs. 7.0), as well as for the outcome variables.

Although comparisons of this sort are effective means of evaluating relative differences between hospitals, there are two major limitations. First, they are unwieldy: one must constantly refer to one table and then another in a time-consuming and potentially error-prone manner. Second, a significant amount of subjective judgement is called for when hospital-specific values differ from the statewide norms. In the case of the above-listed variables for Hospital A, such judgement is not difficult since its values were radically different (often by more than a factor of two) than the statewide values. For other hospitals, the comparison may not be as clearcut. The problem is compounded by the differing degrees of variation between variables; i.e., some variables may have a wide range of values, while others may not.

As an alternative, all variables for each hospital are ranked from their lowest to highest values, then the ranks are converted to percentage points, or percentiles, ranging from a fraction over zero to 100 percent. This method has the advantage of conveying the extent by which a value differs from the norm, yet is entirely self contained. Although the technique could be applied to individual years, only the 1970-77 totals are reported in the interest of limiting the size of this report. Those hospitals that obviously do not have obstetric services by virtue of sporadically reporting a few emergency births were excluded from the ranking. The criteria for exclusion is, of course, arbitrary, but was chosen somewhat conservatively as: (1) included hospitals must report births for more than two years during the eight-year period; and (2) included hospitals must report more than five births per year over the period for which births were reported. Application of the above criteria reduced the total number of hospitals reporting at least one birth over the eight year period from 503 to 441.

The results of the percentile rankings are tabulated in Table 10 in the row labelled "PRCNTL." We see that Hospital A does indeed rank high in terms of the variables BLACK, NOPRE, OUTWED, SHORT, TEEN, PARA6, and LOBW, since percentiles for these variables in Hospital A are all above 90, with most above 95 and one (LOBW) above 99. As a result, all three expected mortality rates lie above the 99th percentile; and, while the observed rates also rank high, they lie below the expected rates, leading to low ranks for the adjusted mortality ratios. Because the ISFMR, ISNMR, and ISPMR indexes are more sensitive to sampling error than the Bayesian indexes or the standard normal test statistics, there is more consistency in the ranks of the latter two measures compared with the former. In summary, the percentile ranking technique provides a rapid and efficient means for assessing a particular hospital's characteristics relative to 440 others during the 1970-77 sample period. Yet percentile values cannot totally supplant the actual values for most variables, since the raw percentages provide the ultimate guideposts for comparison.

Turning to the second sample hospital in Table 10, Hospital B actually ranks highest in BSPMR for the entire group of 411 hospitals over the eight-year sample period. It is seen to have a large and rapidly-increasing proportion of black deliveries with an exceedingly large and growing fraction of out-of-wedlock births, and the proportion of teenage deliveries is above average as well. Hospital B provides an interesting contrast with Hospital A since both have maternal risk profiles that are similar in many ways; cf. BLACK, OUTWED, SHORT, TEEN, etc. They differ dramatically, however, in one important respect, i.e., the proportion of mothers having no reported prenatal care is nearly ten times higher in Hospital A, and Hospital B actually has a lower value for that variable than the statewide average. It is perhaps for this reason that the percentage of low birth weight deliveries and the expected mortality rates are significantly lower in Hospital B. Yet, in spite of its considerably lower expected rates, Hospital B has observed rates that are nearly as high as those in Hospital A and hence its adjusted mortality indexes are very high; i.e., its risk-adjusted perinatal mortality rate is 23 percent above the state average ($P < .0001$), with the neonatal and fetal components 24 percent and 12 percent above average, respectively.

Hospital B therefore provides a polar case to Hospital A even though many of their maternal risk indicators are similar. Recall for Hospital A we concluded that the most urgent action should be to increase access of its obstetric patients to prenatal care, and that intra- and postpartum care appeared adequate. But the opposite holds true for Hospital B where the level of prenatal care appears above average and the effectiveness of intra- and postpartum care ranks as the poorest in the state. These results have clear implications for remedial action that should be taken to lower the crude perinatal mortality rate: improve prenatal care in Hospital A, and intra- and postpartum care in Hospital B. The fact that BSNMR > BSFMR in Hospital B suggests that attention should first be given to its neonatal care component.

Consider next Hospital C in Table 11 with a small, but slowly growing delivery service exhibiting an OBPMR somewhat higher than the statewide average. The change in the ethnic mix of newborns from white non-Spanish to white Spanish has been quite dramatic, moving from a 75/22 ratio to a 36/53 ratio over the eight-year period. Concurrently there was an increase in the NOPRE, OUTWED, and PARA6 variables. Since Hospital C is located in an agricultural region in the Central Valley, it might therefore be conjectured that a significant proportion of the increase in the number of deliveries could be attributed to migrant farm workers. However, in spite of the increase in several maternal risk indexes, there was no corresponding increase in the proportion of low birth weight deliveries or, with the exception of 1977, in the expected mortality rates. This is not atypical of hospitals having large Hispanic populations: i.e., high values for traditional maternal risk indicators are often uncorrelated with low birth weight among Hispanics.

As indicated by the large and statistically significant ($P < .0001$) value for ISPMR, the effectiveness of perinatal care in Hospital C is much lower than average. Its BSPMR of 120.9 indicates that the chances of perinatal death are 21 percent above average after adjusting for newborn risk; and adjusted outcomes tended to be better in 1970-71 than in later years. Both the fetal and neonatal components of perinatal mortality are also statistically significantly higher than average. This finding is especially interesting in light of the small sample size for Hospital C, since statistically significant results are more likely with larger samples.

Hospital D in Table 11 provides an example of an obstetric unit that began its service in 1973 with 1800 deliveries and grew rapidly thereafter, reaching 4100 deliveries by 1977. During this period of growth there was a rapid shift from a predominately black ethnicity to one that is now primarily Hispanic: from a 28/69 black/Hispanic ratio in 1973 to a 66/28 ratio in 1977. During this time there were also marked changes in the maternal risk and newborn variables. For example, NOPRE, OUTWED, TEEN, and LOBW registered sharp declines. The expected rates responded to these declines, but still remained above statewide averages, reflecting the high risk nature of Hospital D's obstetric patients. The observed rates also declined, but not as rapidly, resulting in an increasing trend for the adjusted rates. Hospital D's BSPMR of 117.3 lies near the 99th percentile and its BSNMR of 132.6 is the highest in the state; however its BSFMR is considerably lower (107.3), lying at the 78th percentile. Although it is risky to interpret a trend based on only five years, it appears that there is an upward trend in the standardized rates. One might conjecture, therefore, that the number of deliveries grew faster than the hospital's ability to provide effective services.

Both Hospital C and Hospital D show a definite need for improvement in the effectiveness of obstetric and newborn care. There is also a need to improve the level of prenatal care, especially for Hospital D. Indeed, the latter shows an urgent need for additional resources directed toward all aspects of maternal and infant care.

In response to the contemporary debate regarding eletronic fetal monitoring, cesarean section, and other technological interventions in obstetrics [2], two hospitals having unusually high cesarean section rates (CSEC) are presented in Table 12. Hospital E has a large and growing obstetric service with an increasing proportion of Hispanics, but nonetheless has a low risk population by most measures of maternal risk resulting in expected mortality rates that are significantly below average. In spite of its apparently low risk population, it recorded a 1970-77 CSEC of 15.5 percent, far above the statewide average of 10.8; moreover, its CSEC stood at an alarming 21.9 percent in 1977. Yet there is no evidence of adverse outcomes, with a BSPMR 6.2 percent below the state average ($P < .20$), standing at the 15th percentile. Moreover, the fetal component was 13.8 percent below the mean ($P < .05$), falling below the 10th percentile. The fact that BSFMR is the major contributor (as opposed to BSNMR) to the low BSPMR is noteworthy since it is thought that skillful obstetric intervention can be effective in reducing the risk of intrapartum death.

Hospital F, while much smaller in terms of deliveries than Hospital E, also has a 1970-77 CSEC of 15.5 percent with the rate rising above 24 percent in 1976 and 1977. Its maternal and newborn risk variables also do not appear to warrant such a high CSEC. And, as contrasted to Hospital E, Hospital F's BSPMR is 12.3 percent *above* average ($P < .02$) lying at the 94th percentile, with BSFMR at 22.2 percent above average ($P < .005$), lying at the 98th percentile.

These two examples demonstrate that radically different outcomes occur in the face of high CSEC's. More importantly, they suggest that the CSEC variable should be interpreted in conjunction with the outcome indexes and other variables. In particular, the high CSEC in Hospital E may well be reflective of a sophisticated obstetric service, while that is unlikely to be the case for Hospital F in view of the small number of deliveries. Indeed, sophisticated technology may not be appropriate in smaller obstetric services.

As the final contrast, we have selected two hospitals known to be characterized by the availability of specialized staff and facilities. Hospital G in Table 13 has a very large and growing delivery service showing a shift in ethnicity from white non-Spanish to black and other. Its maternal risk factors and expected mortality rates are lower than average, especially in view of the relatively high proportion of black deliveries. The CSEC variable was far above average at the beginning of the decade, resulting in an above-average rate over the sample period, but by 1977 its CSEC value was not markedly high. Its 1970-77 BSPMR was 15.3 percent below average, ($P < .0001$), which is traced to the neonatal component (BSNMR = 74.6, $P < .0001$), but the fetal component (BSFMR = 100.4, $P > .9$) was average. Note that BSPMR differs little from ISPMR, due to the very large sample size.

Hospital H in Table 13 has a moderately large delivery service with an above-average proportion of births classified by ethnicity as "other." Although most of its maternal risk indicators appear somewhat below average, it has an above-average proportion of low birth weights and high expected mortality rates. Because Hospital H is a major tertiary referral center, there is likely to be a high degree of medical risk inherent in its patients that is not reflected by the crude maternal risk factors available in the MCHDB. The only clues of a selectivity toward higher medical risk is provided by the above-average proportion of multiple births and those to older primigravidas in Hospital H. In any case, the proportion of low birth weights and the expected mortality rates show an increasing trend, consistent with the regionalizing of perinatal health services.

As might be expected for this well-known center for teaching and research, the risk-adjusted mortality rates are very significantly below average with BSPMR at -20.9 percent ($P < .0001$), BSNMR at -22.5 percent ($P < .0001$), and BSFMR at -14.7 percent ($P < .02$). Its above-average cesarean section rate is therefore probably warranted by high risk medical conditions which are not easily measured by means of vital records.

F. By Hospital Characteristics

Data from the MCHDB have been presented on five different levels of aggregation: beginning with the entire state, then by HSA, county, HFPA, and finally on the hospital-specific level. The higher levels were created by adding hospital-specific counts according to the geographical location of each hospital. This procedure can also be applied using other hospital characteristics, e.g., size of delivery service, type of ownership, level of care, etc.

1. Size of Delivery Service

Table 14 presents the characteristics of the distribution of the 1970-77 birth cohort by the average annual number of deliveries. As explained earlier, there tends to be an artificial downward bias to this distribution since we have tabulated *all* births, regardless of whether they were emergency deliveries in non-maternity hospitals, or occurred in hospitals that were either gearing up or winding down their obstetric services. In spite of this bias, it is clear that there is a preponderance of small services in California, with more than three-quarters of all hospitals having less than 1001 annual births, and more than one-half having 500 or fewer births per annum. Yet, somewhat paradoxically, more than 60 percent of all births occur in hospitals having more than 1000 annual births, with more than 30 percent taking place in the 35 hospitals having more than 2000 births annually.

The definition of size categories, especially the smallest, warrants special comment. As explained earlier, size of delivery service is inherently a very dynamic characteristic, with many hospitals displaying significant upward or downward trends. To classify each hospital by size over the sample period, we examined each trend to estimate the number of years of active obstetric services. Average deliveries per year was then computed by dividing total deliveries (1970-77) by the number of active years. In California a small yet significant number of hospitals and clinics are licensed for obstetric services, but no longer have active delivery units. Sporadically, however, an emergency delivery occurs in such institutions. Because the sitution is fluid in this regard, it is difficult to form quantitative criteria for classifying a hospital as active or inactive over the entire eight-year sample period. Yet it seemed desirable to classify inactive units as a separate category. As a first approximation inactive units were defined as those having five or fewer births per year (this definition parallels the criteria used to create the percentiles in Table 15). The number was set purposefully low to avoid classifying small rural units as inactive. The smallest "size" category, therefore, should be interpreted not as the very smallest of delivery units, but as a group of licensed but inactive institutions having sporadic emergency deliveries. Although it is virtually certain that the hospitals in this category are inactive, there are probably a small number of inactive hospitals that fall into the remaining five size groups. Two additional "size" categories are provided to insure that all births can be classified according to this characteristic: i.e., nonhospital births and hospital births that cannot be traced to a specific hospital.

From Table 14 we see that only 182 births occurred in the 39 hospitals considered inactive during the 1970-77 sample period. With such a small number of events the results should, of course, be cautiously interpreted. Yet the emergency nature of births in this category is manifested by the extremely high values for NOPRE and LOBW as well as all of the outcome variables. It is clear the probability of perinatal death is very high, both the expected and the observed, under these conditions. Further, it also appears that the greatest risk is for the fetal component, thus suggesting (along with the high proportion of low birth weights) that many of these are premature emergency deliveries brought about by unexpected precipitant labor. The highly significant values for ISFMR and BSFMR suggest that these inactive hospitals are poorly equipped to deal with such emergencies. On the other hand, the small value for ZNMR indicates that a live-born infant has a nearly average chance for survival under these conditions.

Further inspection of Table 16 reveals some interesting trends for the remaining size categories:

(1) As size increases the proportion of white non-Spanish births decreases, which is reflected by increases in the proportions of Hispanic, black, and other ethnicities.

(2) The proportions of out-of-wedlock and adolescent births decrease with increasing size.

(3) The proportions of older, older primiparas, multiple births, and cesarean sections increase with size.

(4) The percent low birth weight increases somewhat with size.

(5) The expected perinatal mortality rate, as well as its components (EXFMR and EXNMR), increases with size.

(6) There is no apparent relationship for the observed mortality rate with increasing size.

(7) All of the indirectly standardized rates (perinatal, neonatal, and fetal) decrease with increasing size, as do their respective standard normal test statistics.

These observations are consistent with larger proportions of minorities and high risk patients giving rise to higher expected mortality rates in the larger institutions, but with the larger units having more effective intra- and postpartum care. The observed rates, therefore, show no clear trend since risk is offset by effectiveness as size increases. For all three standardized rates however, there is a marked decrease with increasing size. The adjusted perinatal mortality rate is more than 13 percent lower in the largest size service compared with the smallest active size group (110.9 - 97.5 = 13.4). This differential increases to 20.5 percent (116.1 - 95.6) for the adjusted fetal mortality rate. These results give unambiguous statistical proof to the notion that childbirth is safer (for the infant) in larger hospitals. Note, however, that the largest gradient occurs in the smaller categories and that the decreases in adjusted rates associated with larger sizes are not appreciable in their magnitudes. In short, there is little to be gained by size alone after 500 annual deliveries, with the maximum differential in BSPMR of 3.6 percent above that size.

The two remaining "size" categories, nonhospital births and births and unidentified hospitals, constitute a residual category necessary to completely describe birthing activities throughout the state. The former will be described in more detail in Sec. III.F.4, but it is clear that births in a nonhospital setting are riskier both in terms of expected and observed mortalities. As will be explained later, however, there were some rapidly changing trends during the sample period with respect to nonhospital newborn risk and outcomes. The unknown size category is also characterized by higher expected and observed mortality rates. This finding may be explained in part by the nature of the "unknown" group. That is, when a birth certificate is reported in a hospital not recognized by Vital Records staff, it is often a hospital without licensed maternity services, and thus may resemble the inactive classification discussed earlier.

2. Hospital Ownership

Table 15 presents information from the MCHDB by type of hospital ownership or control. Because the relationship between ownership and the 31 variables is more complex than was the case for size of delivery service, results in each type of ownership category are discussed separately.

Private Nonprofit(NONPROFIT)

This is by far the largest group both in terms of number of deliveries and number of hospitals. The values for most of its variables, therefore, lie near the statewide average values. When they differ, however, the NONPROFIT category tends toward lower risk values for the maternal risk variables and for low birth weight; consequently, the expected mortality rates for NONPROFIT fall, as would then be anticipated, below average. And, with the observed rates lower still, the adjusted rates are also below the statewide average, with the adjusted fetal rate somewhat lower than the neonatal component. In a sense, the NONPROFIT group might be considered as the "mainstream" of health care, and thus could be considered the norm, in place of the statewide standards, for purposes of comparison.

Private Proprietary(PROFIT)

The next most populous group in terms of both the number of hospitals and number of deliveries is the private proprietary, or for-profit ownership. As contrasted to the NONPROFIT group, the PROFIT category has generally smaller delivery services since it has only 38 percent fewer hospitals, but 72 percent fewer births. Compared to NONPROFIT, the PROFIT group has relatively more Hispanic, adolescent, multiparous and out-of-wedlock births, with the remaining maternal risk indicators essentially equal. This equivalency is reflected by the similarity in expected rates. For the observed rates, however, the PROFIT group has consistently higher values, yielding adjusted rates significantly above average with a differential between PROFIT and NONPROFIT of up to 12.5 percent for the fetal component. Because the PROFIT group is characterized by an abundance of small hospitals, this finding is consistent with the findings related to size as reported in Table 14; i.e., smaller hospitals have higher risk-adjusted mortality rates. Therefore, the extent to which the PROFIT-NONPROFIT differentials are due to type of hospital ownership cannot be identified from Table 15 alone.

County/City (LOCAL)

Hospitals under the jurisdiction of city or county (local) governments play an important, but currently financially threatened, role in the delivery of helth services to California's poor. The high risk status of their obstetric patients is apparent from the large values in Table 15 for SPAN, BLACK, NOPRE, OUTWED, SHORT, TEEN, and PARA6. It follows, therefore, that the percentage low birth weight and expected mortality rates are among the highest of any hospital group. And, to make matters worse, the observed rates are even higher than those expected, yielding an ISPMR statistically significantly ($P < .0001$) above average at 105.6. The OBPMR is thus the highest of any of the (known) hospital groups. These results parallel those for Hospital D in Table 11, which was indeed a county-owned hospital, in that both antepartum as well as intra- and postpartum care appears to be lacking for patients who deliver in local government hospitals.

Kaiser Foundation (KAISER)

The not-for-profit Kaiser Foundation hospitals belong to the Kaiser-Permanente Medical Care Program, a large prepaid group practice plan. While ownership of hospitals in this group could be validly classified as nonprofit, their common ownership and other special characteristics warrant their being treated as a separate class. There are several salient features in Table 15 relative to hospitals in the KAISER group. First, they have very large delivery services as evident from the fact that they represent three percent of all hospitals in Table 15, but account for 10 percent of all births. Indeed, six of California's seventeen largest hospitals in 1977 (those having more than 3,000 live births) belonged to the KAISER group, with the third and fourth largest of Kaiser ownership. Secondly, they are characterized by very low values for the maternal risk variables, e.g., OUTWED, SHORT, TEEN, and PARA6. Consequently, the proportion low birth weight and expected mortality rates for the KAISER group are the lowest of any class in Table 15. The observed rates, also, are quite low; but as they are slightly larger than the expected, the indirectly standardized ratios are marginally greater than 100, with the ISPMR bordering on the level of statistical significance ($P < .10$).

The source of low maternal risk among KAISER obstetric patients can probably be traced to the criteria for enrollment, which implicitly include stable employment by either the patient or her spouse (note the very low value of 6.5 percent for the OUTWED variable). Yet the standardized mortality indexes above 100 for the KAISER group are of concern, especially when compared to those for NONPROFIT in Table 15 and the > 2000 category in Table 14. Thus, as contrasted to the PROFIT group, the higher standardized rates for Kaiser hospitals cannot be explained by size of delivery service. Although the complete explanation to this finding is undoubtedly complex, there is some evidence that the KAISER group lagged in the adoption of intervention-oriented obstetric technologies during the 1970's, especially with respect to cesarean section [2].

District (DISTRICT)

District hospitals are frequently found in rural areas in California where a hospital district is formed to satisfy unmet needs. As a result, they are likely to serve a relatively heterogeneous population. But, perhaps due to their more rural nature, the ethnicity and maternal risk variables suggest a low risk population as evidenced by the values for the expected mortality rates, which are only slightly higher than the KAISER group. The OBPMR is also low, but like KAISER, it is slightly larger than EXPMR, yielding an ISPMR just above 100, though not statistically significant. An interesting unbalance occurs for the components of adjusted perinatal mortality with neonatal rate slightly above average and the fetal rate slightly below, both bordering on the level of statistical significance.

Federal (FEDERAL)

Federally-owned hospitals in California having obstetric services are composed solely of military facilities serving armed forces personnel and their dependents on a low/no-cost basis. It is clear from Table 15 that they are radically different in terms of ethnicity and maternal risk. Very low values are observed for SPAN, NOPRE, OUTWED, TEEN, OLDER, OPARA1, and

PARA6: while values for OTHER and PARA1 are above average. Predictably then, the proportion of low birth weights and expected mortality rates below average, and with the observed perinatal mortality rate lower yet, the ISPMR is 4.2 percent below the statewide average ($P < .05$), with an BSFMR 9.9 percent below ($P < .001$), yet the BSNMR is not significantly different from average ($P > .8$). It is interesting to note that these results were obtained in the face of a cesarean section rate that is the lowest of the hospital groups.

State(STATE)

With one minor exception,* all of the State-owned hospitals in California having obstetric services are affiliated with the University of California. All five are large, teaching and research-oriented secondary or tertiary referral centers. Not surprisingly, their ethnicity and maternal risk factors are similar to their county/city-owned counterparts. And, as is anticipated, their expected mortality rates are very high, even higher than those in the LOCAL group. This added risk is probably the result of the referral of women with high medical risk factors which are not easily measurable using current birth certificate data. As opposed to the LOCAL group, however, the observed mortality rates are lower than those expected and the smallest ISPMR is obtained for this group at 6.6 percent below average ($P < .0005$). This result appears to stem from both the neonatal and fetal components, with a somewhat lower adjusted fetal rate. Here, however, as opposed to the FEDERAL group, the cesarean section rate is the highest of any group; once again demonstrating that the effectiveness of perinatal care is a complex phenomenon, not easily predicted by a single variable.

3. Hospital Peer Groups

In addition to such obvious and easily quantified measures as ownership and size, hospitals display other characteristics which may influence their behavior and performance. For example, a hospital with a strong teaching program is likely to differ from one of equal size and ownership that has few residents and interns. Or, a small hospital in a rural setting may be quite different than a small urban one. In an effort to provide more meaningful cost comparisons between hospitals, the California Health Facilities Commission (CHFC) has applied a statistical clustering technique to classify many of California's hospitals according to peer groups. The technique uses a computerized algorithm based on the following variables: scope of service index, average number of beds, proportion of adult patient days by diagnosis, proportion of pediatric patient days, proportion of psychiatric patient days, proportion of intensive care patient days, number of residents and interns, and percent of county population living in rural areas. Based on values for these variables, hospitals are assigned into one of ten groups, six of which are relevant here: teaching, large-urban, average-urban, small-urban, average-rural, and small-rural.

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*A women's prison reported 108 births over the 1970-77 period; but as the delivery unit differed so dramatically from the remain five state-owned hospitals, these births were assigned to the UNKNOWN ownership category in Table 16.

Table 16 presents the MCHDB results according to these six peer groups. As is to be expected, the 13 hospitals belonging to the teaching group exhibit values very similar to the five University of California (UC) hospitals in Table 15, with high values for SPAN, BLACK, NOPRE, OUTWED, SHORT, TEEN, OLDER, and PARA6. The expected mortality rates in teaching hospitals are therefore correspondingly high. But, as was the case for the UC hospitals, the observed rates are lower than the expected, yielding a standardized perinatal mortality ratio that is significantly ($P < .05$) below the state average.

Turning to the non-teaching urban hospitals in Table 16, we find that the effectiveness of perinatal care varies inversely with size, consistent with the results in Table 14. Further, it appears that the disparity by size in standardized ratios is higher for the fetal component of perinatal mortality, with a 14.4 percent differential between the small and large group. An interesting result is the average values for most of the MCHDB variables in the average-urban CHFC group, thus validating the classification technique.

As expected, hospitals falling in the rural group are characterized by generally lower risk-related values, but by high standardized mortality ratios than their urban counterparts. And, consistent with the urban results, size displays an independent effect for rural hospitals, leaving the small rural hospital as the most hazardous in terms of risk adjusted perinatal mortality.

4. Out-of-Hospital Births

In recent years out-of-hospital births (OHB) have become increasingly more common. During the decade of the 1960's, the annual percentage of out-of-hospital births was consistently about one-half of one percent. Beginning in the early 1970's the incidence of OHB gradually increased, and by 1977 the proportion stood at 1.4 percent (Figure 10). During this period, twelve of California's fifty-eight counties had average values above two percent. Most of these were sparsely populated counties having relatively few births where the higher proportion of nonhospital deliveries is likely to be the consequence of reduced hospital access due to long distances. Yet three of these counties -- Marin, Santa Cruz, and Sonoma, with OHB's of 10.6 percent, 8.2 percent, and 6.4 percent, respectively -- are not sparsely populated, have more than 1,000 births per year, and have readily-accessible hospitals. These rates thus reflect the decision by increasing numbers of couples to elect a home delivery, commonly thought to be a consequence of a growing dissatisfaction with the impersonal facets of hospital care, stemming in part from the rapid increase in the degree of technological intervention in obstetrics. Escalating hospital charges in the face of a relative lack of insurance coverage for pregnancy are also potential causes.

From Tables 14-16 it is clear that OHB's differ from hospital births by several measures, with the most noticeable including NOPRE, TEEN, PARA1, PARA6, LOBW, EXFMR, EXNMR, and EXPMR. That is, OHB's are characterized by little prenatal care, few adolescent mothers, relatively few primiparas, proportionately more grand multiparas, low birth weight, and high expected mortality rates. Because of these differences, and because of the rapid changes taking place, time trends for a few of these variables for hospital vs. nonhospital location are presented in Figures 11-15.

Figure 11 reveals a decreasing trend for the proportion of grand multiparas, especially for OHB's. The more rapid decline for OHB's is suggestive of a decreasing fraction of accidental deliveries, some of which may have been attributable to precipitous labor associated with grand multiparity. More rapidly declining trends for nonhospital vs. hospital births occurred as well for several other maternal risk indicators, including TEEN, OLDER, SHORT, and OUTWED. In each case there was a higher proportion of high risk women in the OHB group at the beginning of the decade, but by 1977 these maternal risk indexes for the OHB group were not significantly higher, and in some cases were lower, than those for hospital births. In short, although the maternal risk indicators were high for OHB in 1970, they were essentially average by 1977, resulting in 1970-1977 values which were above average.

The single exception to this pattern is shown in Figure 12 for the proportion of mothers having no reported prenatal care. While the level for this variable has declined by nearly a factor of two, it remains at an unreasonably high rate. When partitioned by ethnicity, it was found to be highest among Spanish-surname mothers. These findings probably reflect the reluctance of physicians to administer prenatal care to women who plan to deliver at home, as well as increasing numbers of illegal immigrants from Mexico who deliver outside of hospitals for fear of deportation. The pattern might also be the result of a causal association between the lack of prenatal care and precipitous labor.

The more rapid trend toward lower maternal risk for OHB deliveries is reflected in the trend for low birth weight (Figure 13), falling from a rate that was more than double the in-hospital group in 1970 to a value slightly lower than the hospital-based value by 1977. Consistent with the trend in low birth weight has been a rapid convergence in the expected perinatal mortality rate for nonhospital deliveries toward the hospital-based norm (Figure 14). The observed perinatal rate has declined for both groups (Figure 15), and as with low birth weight and expected perinatal mortality, it has dropped more rapidly for the nonhospital group. The effectiveness of intra- and postpartum care for the OHB group, as measured by ISPMR, has also improved (Figure 16) for OHB's. At the beginning of the decade, ISPMR for OHB was significantly higher than average, but by 1977 the ratio stood slightly below the statewide norm. Thus, it would appear that, while the increasing trend toward OHB should be carefully monitored, as of 1977 there was no substantive cause for alarm, and in fact, there were overall positive trends during the 1970's. Nonetheless, as the overall 1970-1977 rates indicate in Tables 14-16, a nonhospital delivery has historically been subject to greater risk, and selected geographical areas, especially those having large fractions of Hispanic OHB's should be evaluated carefully. Additionally, attention should be directed toward reducing the high proportion of OHB deliveries having no prenatal care.

IV. SUMMARY

Vital record data provides an efficient means for gathering statistical information which can be useful in the planning of perinatal health services. Because of nearly complete reporting, birth cohort data allows trends in natality and mortality to be accurately monitored over wide geographical areas. The linking of birth and death records within a yearly cohort has resulted in more meaningful infant mortality information and therefore suggests using outcome data on a disaggregated basis. Yet there are a number of hazards in using disaggregated mortality data, principally related to variations in newborn risk and to statistical randomness. It was demonstrated that these hazards can be minimized, though not totally eliminated, by appropriate methods of statistical analyses.

Variations in newborn risk were accounted for by using birth weight and other newborn variables to predict the mortality rate that would be expected for a particular unit of observation (hospital, HFPA, county, HSA). An indirectly standardized mortality ratio was formed by comparing the observed and expected mortality rates. A further statistical adjustment was made to minimize the effect of chance behavior. A standard normal statistic was computed to test the null hypothesis that a particular adjusted mortality ratio was equal to the normative value. These variables were computed for perinatal mortality as well as for its fetal and neonatal components. To better understand the sources of newborn risk variation, a number of crude maternal risk indicators were also derived from the birth cohort data. At present, it is not possible to accurately predict newborn risk from maternal attributes due to data deficiencies. The standardized perinatal mortality rates therefore adjust only for newborn risk factors at the time of birth, and thus measure the efficacy of intra- and postpartum care. In summary, the current statistical methodology is not capable of measuring the contribution of preventive measures in reducing perinatal mortality, but appears to be useful in monitoring the effectiveness of medical care during birth and shortly thereafter.

Risk and outcome variables were reported on several levels of aggregation, starting with the statewide values, which could be used as a basis for comparison. Data were then subdivided by HSA, with a particular HSA chosen to serve as an example. The two counties comprising the sample HSA were then examined. Data for the health facility planning areas within these two counties were discussed next. Finally, hospital-specific results were presented using eight anonymous examples drawn from throughout the state, each illustrating some particular element of risk or outcome. When reviewing numerical results for specific hospitals, the question of comparability with the statewide norms constantly arose and complicated the interpretive process. Consequently, a method of reporting hospital specific data in terms of percentile ranks was devised.

Hospital data were then re-aggregated, but next by type of hospital rather than by geographical location. It was generally found that larger proportions of minorities and high risk patients delivered in the larger delivery units, giving rise to higher expected mortality rates. Yet the results also confirmed the common belief that childbirth is safer (for the same level of newborn risk) in the larger institutions. The results by hospital ownership were diverse, but were highlighted by the polar cases of private nonprofit versus local government hospitals. While the former was charcterized by low risk and low adjusted mortality rates, the latter had above average risk indexes and very high mortality rates. The data were also organized by hospital peer groups based on size, complexity of service, and geographical location. As might be expected, larger more complex hospitals were characterized by lower adjusted mortality rates than were smaller units, especially those situated in rural areas. These and other differences should be kept in mind when interpreting hospital-specific results.

Other limitations and qualifications should also be kept in mind. Specifically, there are: limitations related to the completeness and accuracy of the birth cohort information, qualifications resulting from geographical movements of mothers and newborns, current two to three year lags in the availability of the cohort data, and finally, fundamental statistical limitations on the current method of indirect standardization. For these reasons, the data presented here should not be interpreted in a rigid fashion, but should be viewed as guideposts to be used in conjunction with other sources of information. Indeed, there can be no substitute for accurate, first-hand, current information regarding obstetric and newborn care within a particular community. Yet such information is often unavailable or difficult to obtain. It is hoped, therefore, that the vital record data presented herein can be used constructively to improve the well-being of mothers and infants in California, and ultimately throughout the nation.

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VI. GLOSSARY OF ACRONYMS

Acronym	Where Defined	Meaning
BIRTH	Sec. III.A	Number of births (exclusive of < 501 g and unknown birth weights)
BLACK	Sec. III.E	Percent black births
BSFMR	Sec. II.C	Bayesian standardized fetal mortality ratio (%)
BSNMR	Sec. II.C	Bayesian standardized neonatal mortality ratio (%)
BSPMR	Sec. II.C	Bayesian standardized perinatal mortality ratio (%)
CHFC	Sec. III.F.3	California Health Facilities Commission
CSEC	Sec. III.A	Cesarean section rate (%)
DISTRICT	Sec. III.F.2	Hospital district ownership
E(X)	Sec. II.B	Expected (or mean) value of the random variable X
EXFMR	Sec. II.C	Expected fetal mortality rate (per 1000)
EXNMR	Sec. II.C	Expected neonatal mortality rate
EXPMR	Sec. II.C	Expected perinatal mortality rate
FEDERAL	Sec. II.F.2	Federal government hospital ownership
HFPA	Sec. III.D	Health Facility Planning Area
HSA	Sec. III.B	Health Service Agency
ISFMR	Sec. II.C	Indirectly standardized fetal mortality ratio (%)
ISNMR	Sec. II.C	Indirectly standardized neonatal mortality ratio (%)
ISPMR	Sec. II.C	Indirectly standardized perinatal mortality ratio (%)
IUGR	Sec. II.A	Intrauterine growth retardation
KAISER	Sec. III.F.2	Kaiser Foundation Hospital
LBW	Sec. II.A	Low birth weight (< 2501 g)
LOBW	Sec. III.A	Percent low birth weight births
LOCAL	Sec. III.F.2	Local government (county or city) hospital ownership
MCHDB	Sec. I	Maternal and Child Health Data Base (at U.C. Santa Barbara)
MULT	Sec. III.A	Percent multiple births
NFB	Sec. II.E	Net flow of births
NONPROFIT	Sec. III.F.2	Private nonprofit hospital ownership

Acronym	Where Defined	Meaning
NOPRE	Sec. III.A	Percent mothers with no reported prenatal care
OBFMR	Sec. II.C	Observed fetal mortality rate (per 1000)
OBNMR	Sec. II.C	Observed neonatal mortality rate
OBPMR	Sec. II.C	Observed perinatal mortality rate
OHB	Sec. III.F.2	Out-of-hospital births
OI	Sec. II.E	Occurrence index
OLDER	Sec. III.A	Percent older (> 34 years) mothers
OPARA1	Sec. III.A	Percent older primiparas
OTHER	Sec. III.A	Percent other (non-white and non-black) births)
OUTWED	Sec. III.A	Percent (inferred) out-of-wedlock births
PARA1	Sec. III.A	Percent primiparous mothers
PARA6	Sec. III.A	Percent grand primiparous (parity > 6) mothers
PROFIT	Sec. III.F.2	Private proprietary (for-profit) hospital ownership
RI	Sec. II.E	Residence index
SGA	Sec. II.A	Small for gestational age
SHORT	Sec. III.A	Percent short (< 17 months) interpregnancy intervals
SPAN	Sec. II.E	Percent white Spanish surname births
STATE	Sec. III.F.2	State of California hospital ownership (University of California hospitals)
TEEN	Sec. III.A	Percent adolescent (< 18 years) mothers
UNKNOWN	Sec. III.F.2	Unknown hospital ownership
UO	Sec. II.B	Unit of observation; e.g., hospital, HFPA, county, HSA, etc.
VAR(X)	Sec. II.B	Variance of random variable X
WHITE	Sec. II.E	Percent white non-Spanish births
ZFMR	Sec. II.B	Standard normal test statistics for H_o: ISFMR = 100
ZNMR	Sec. II.B	Standard normal test statistics for H_o: ISNMR = 100
ZPMR	Sec. II.B	Standard normal test statistics for H_o: ISPMR = 100

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FIGURE 1. Intrauterine growth curves and perinatal mortality rates: Total single births - California, 1970-1976.

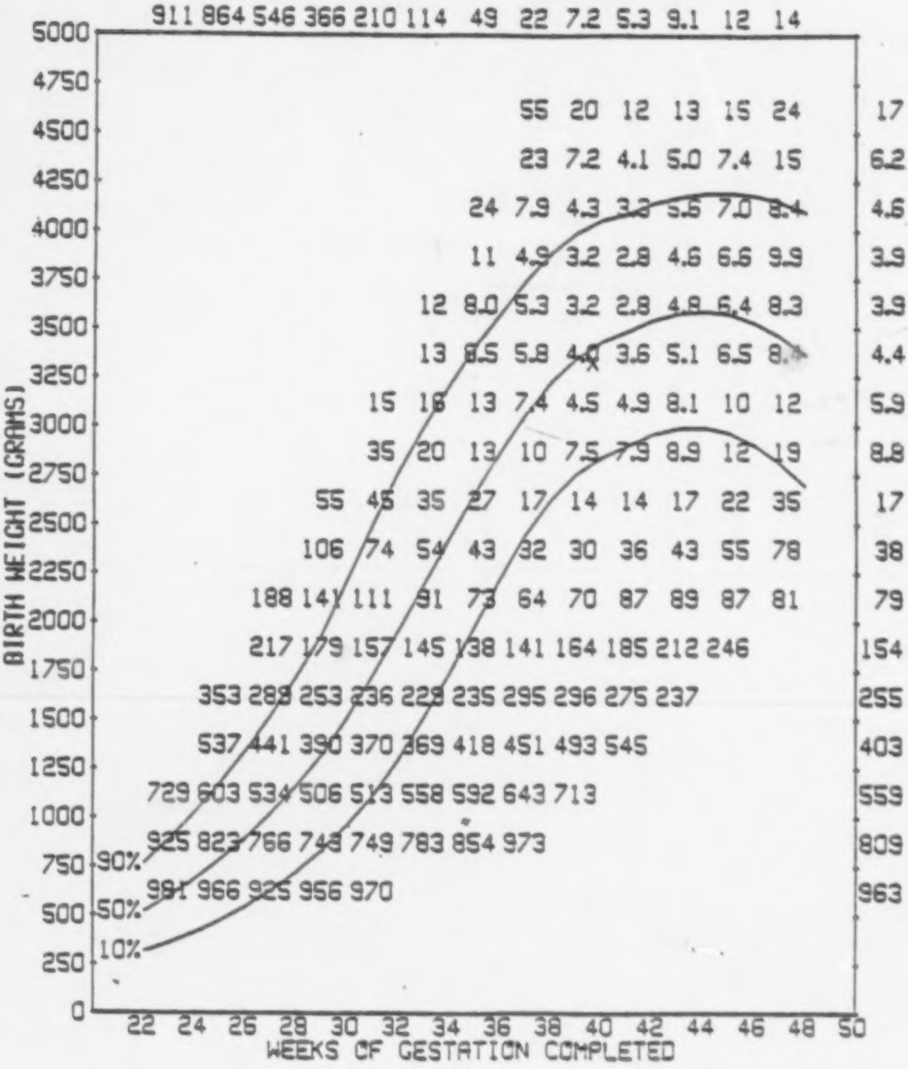

FIGURE 2. Intrauterine growth curves and perinatal mortality rates: Total multiple births - California, 1970-1976.

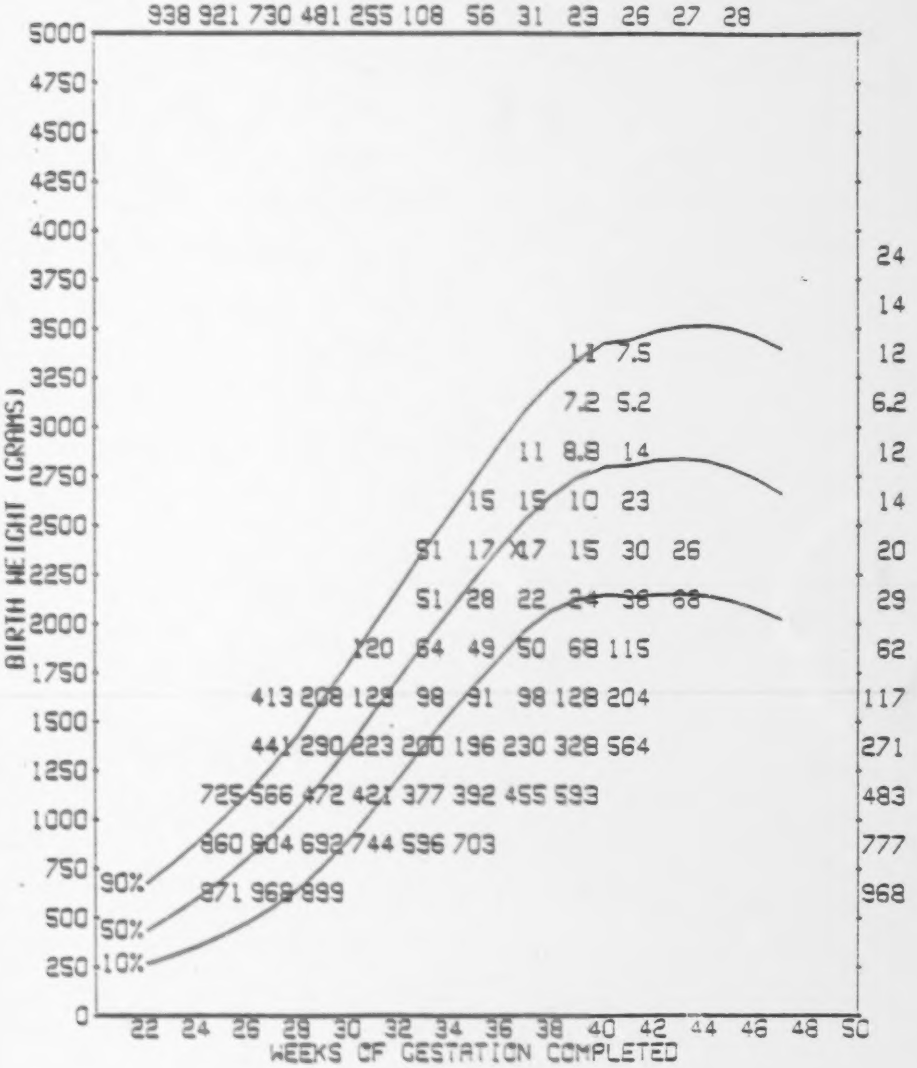

FIGURE 3. Binomial simulation: n = 100, EXPMR = 20.

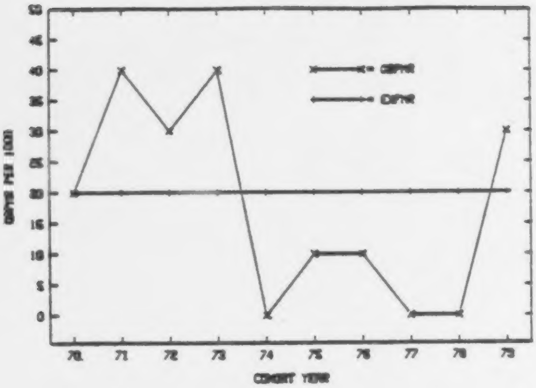

FIGURE 4. Binomial simulation: n = 500, EXPMR = 20.

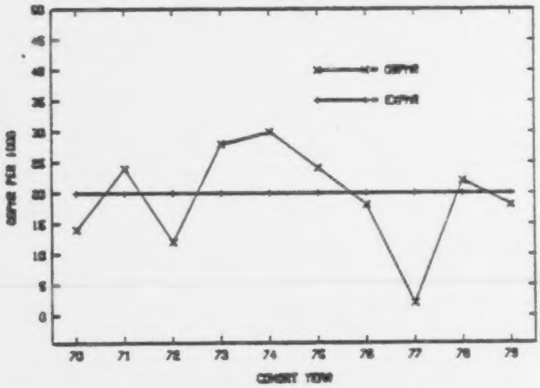

FIGURE 5. Binomial simulation: n = 2000, EXPMR = 20.

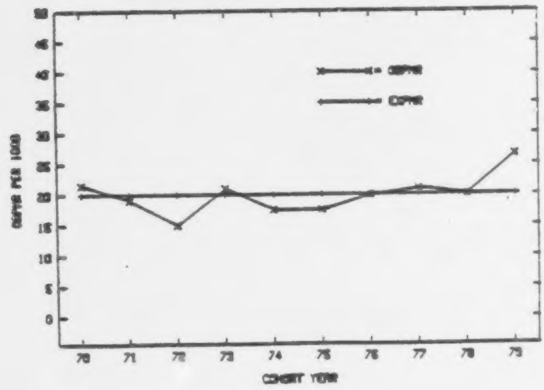

FIGURE 6. Observed perinatal mortality rate (OBPMR) for four levels of aggregation.

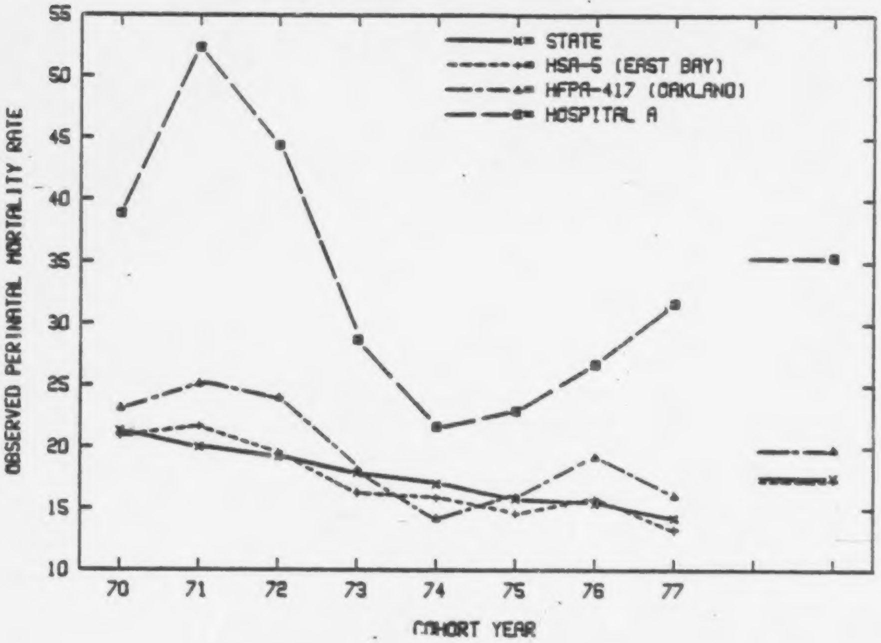

FIGURE 7. Expected perinatal mortality rate (EXPMR) for four levels of aggregation.

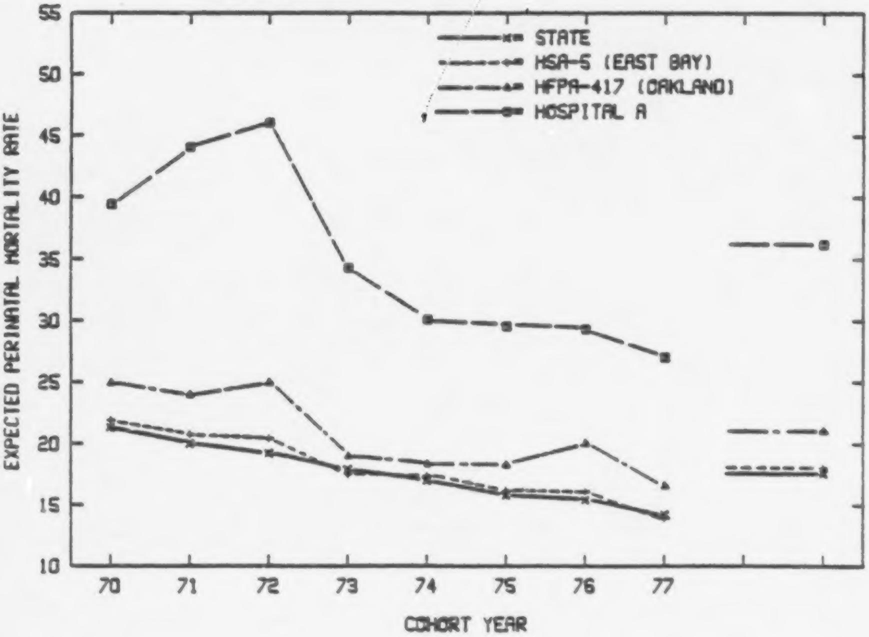

FIGURE 8. Indirectly standardized perinatal mortality ratio (ISPMR) for four levels of aggregation.

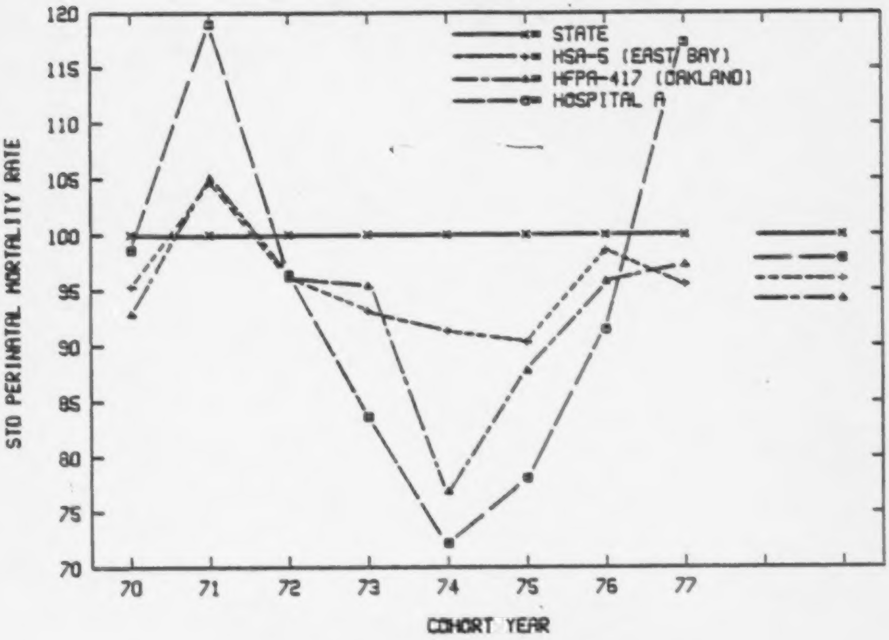

FIGURE 9. Bayesian standardized perinatal mortality ratio (BSPMR) for four levels of aggregation.

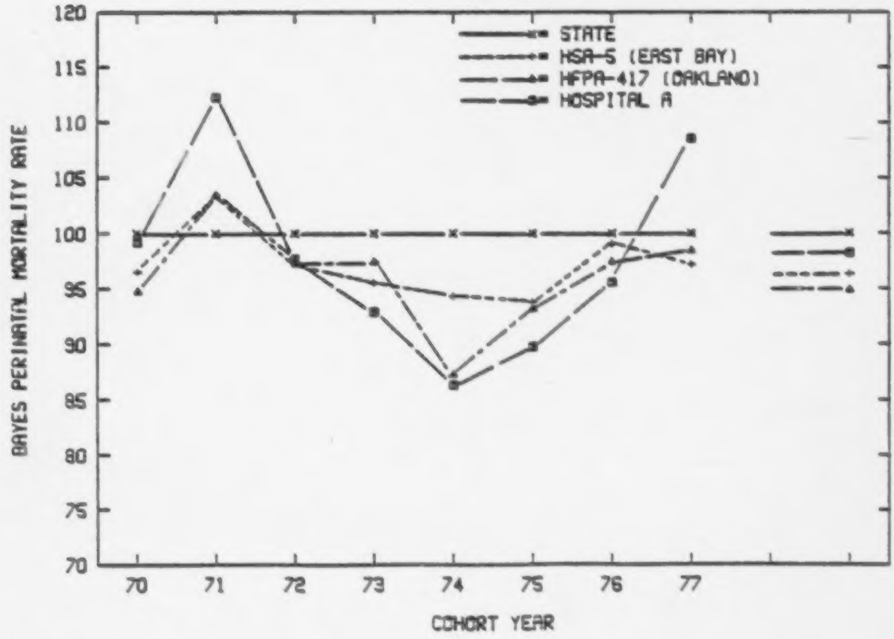

FIGURE 10. Percent out-of-hospital births: California, 1970-1977.

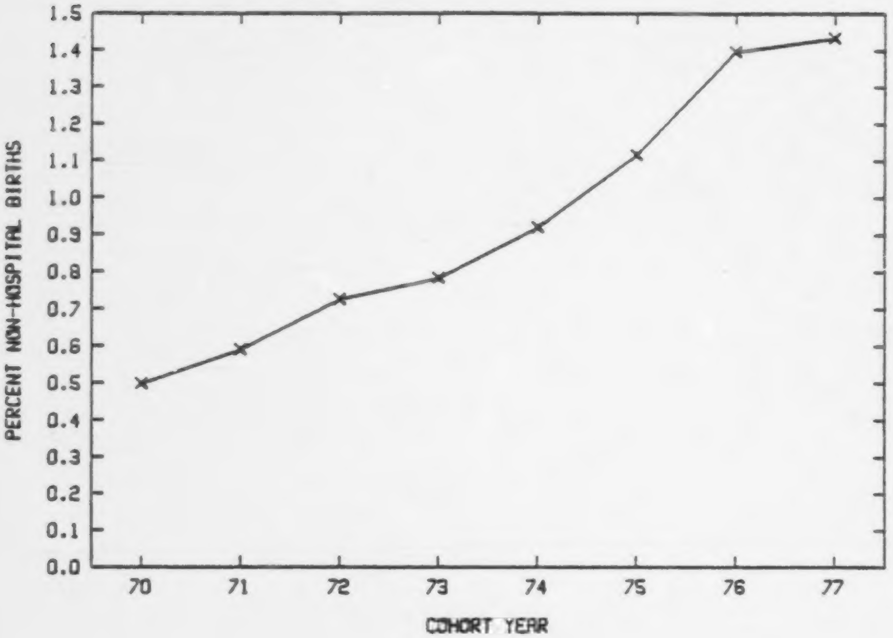

FIGURE 11. Percent births to mothers of parity ≥ 6: California, 1970-1977.

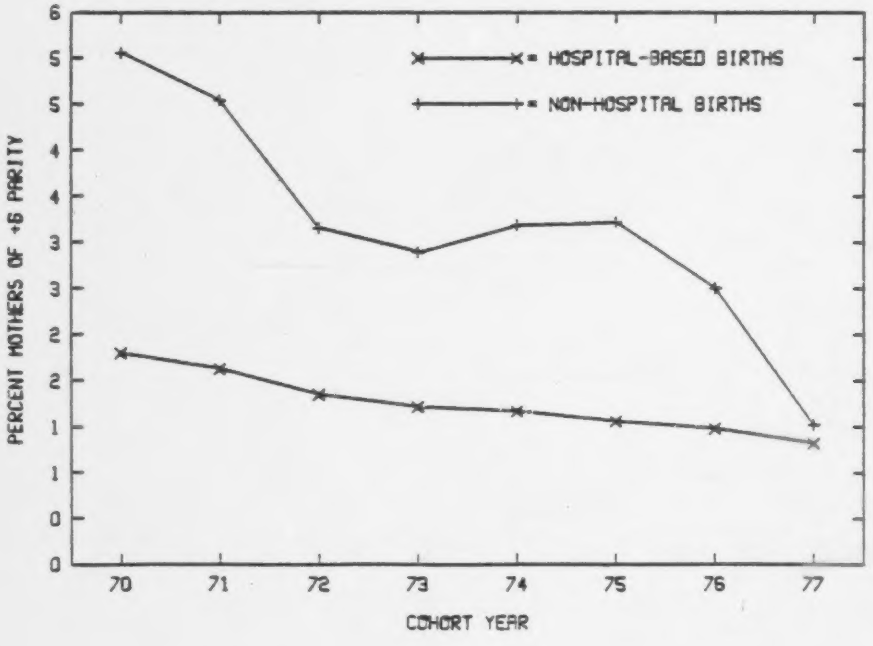

FIGURE 12. Percent births to mothers having no reported perinatal care: California, 1970-1977.

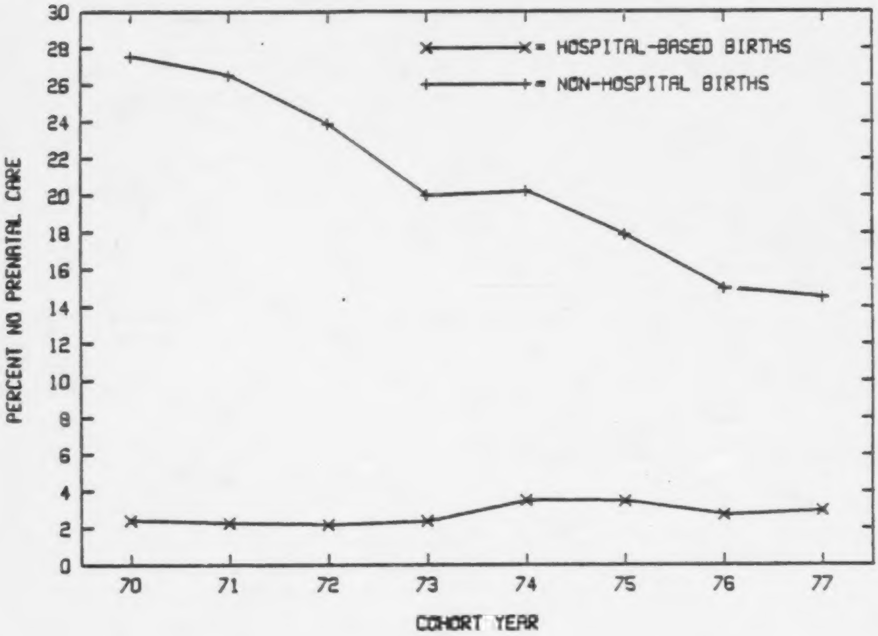

FIGURE 13. Percent low weight (< 2501 g.) births: California, 1970-1977.

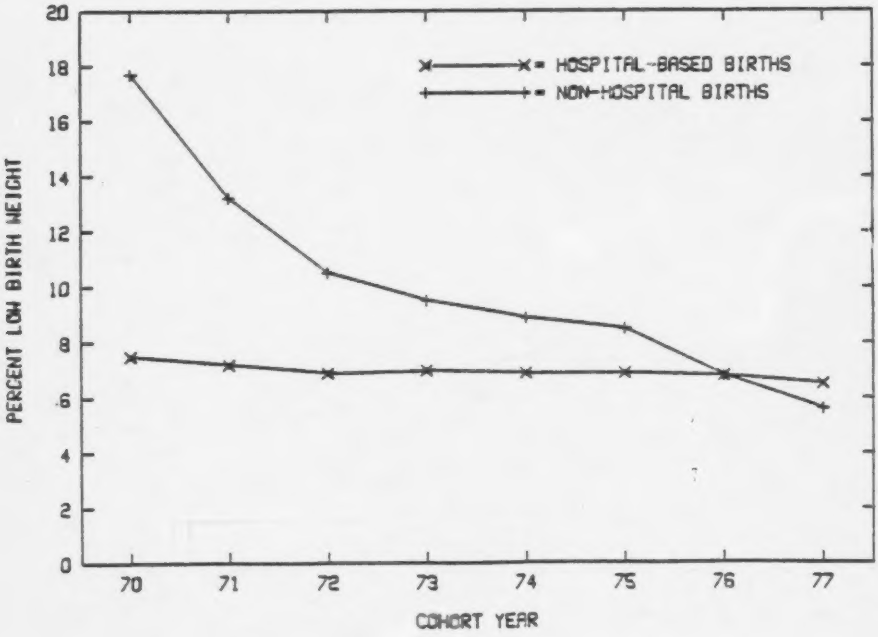

FIGURE 14. Expected perinatal mortality rate per 1000: California, 1970-1977.

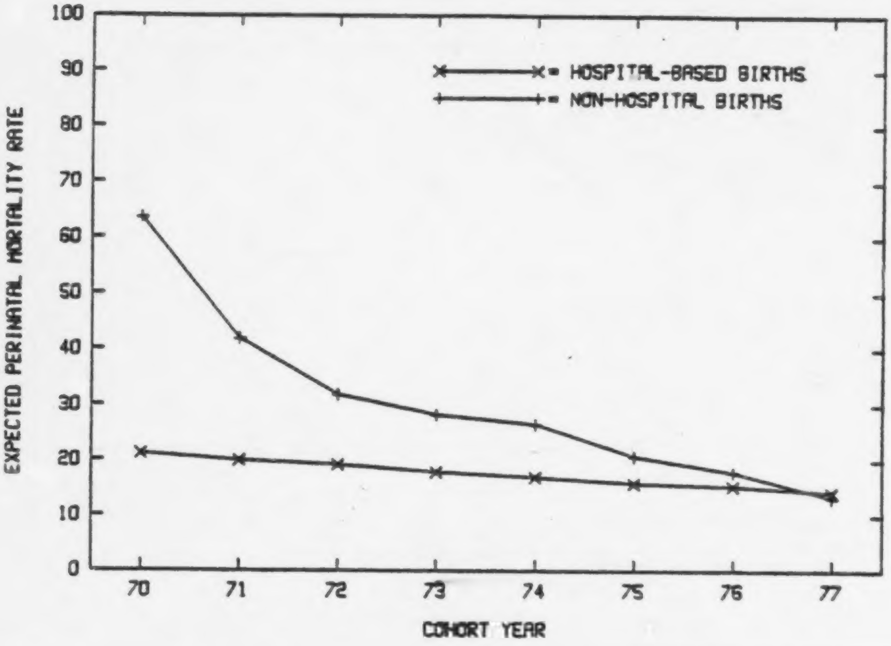

FIGURE 15. Observed perinatal mortality rate per 1000: California, 1970-1977.

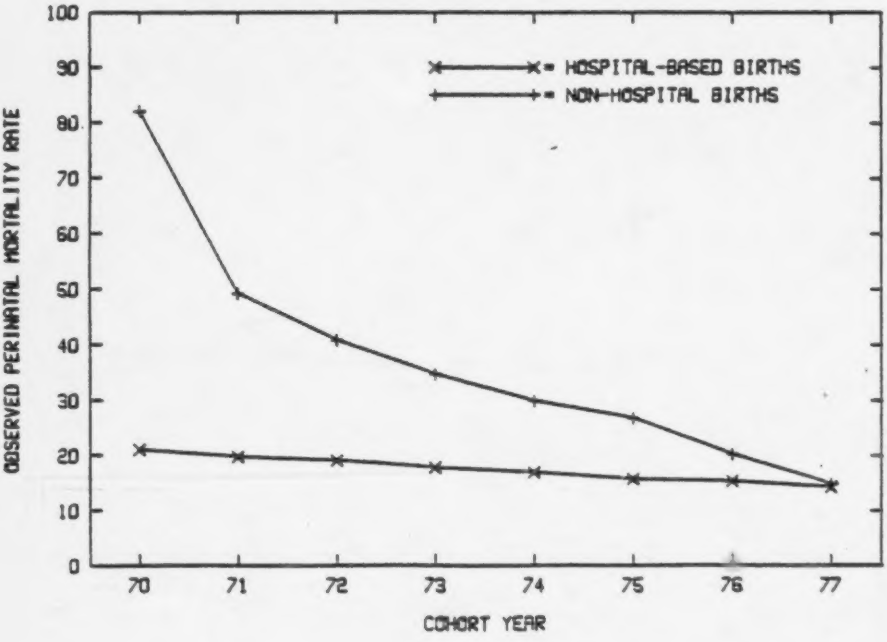

FIGURE 16. Indirectly standardized perinatal mortality ratio: California, 1970-1977.

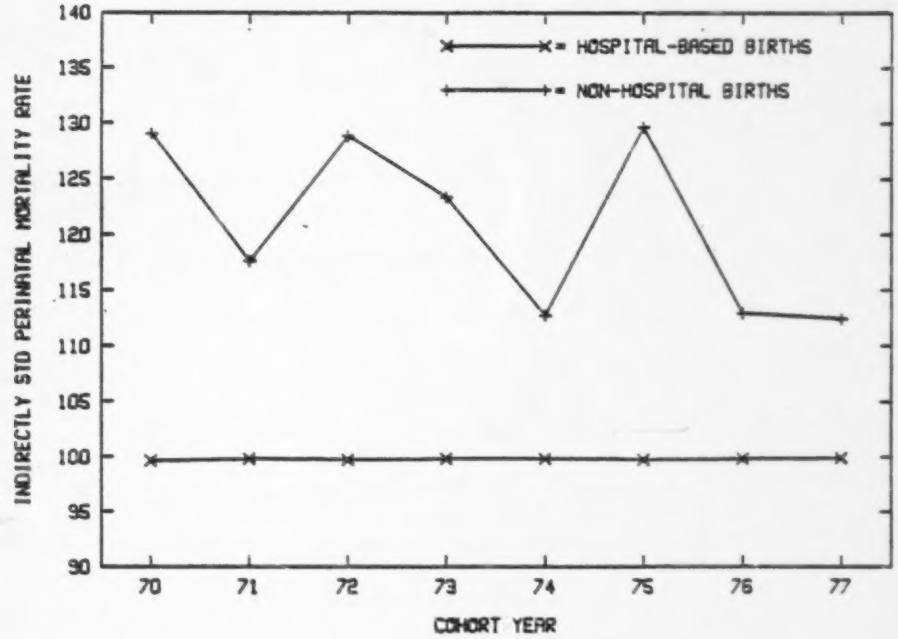

FIGURE 17. Bayesian standardized perinatal mortality ratio: California, 1970-1977.

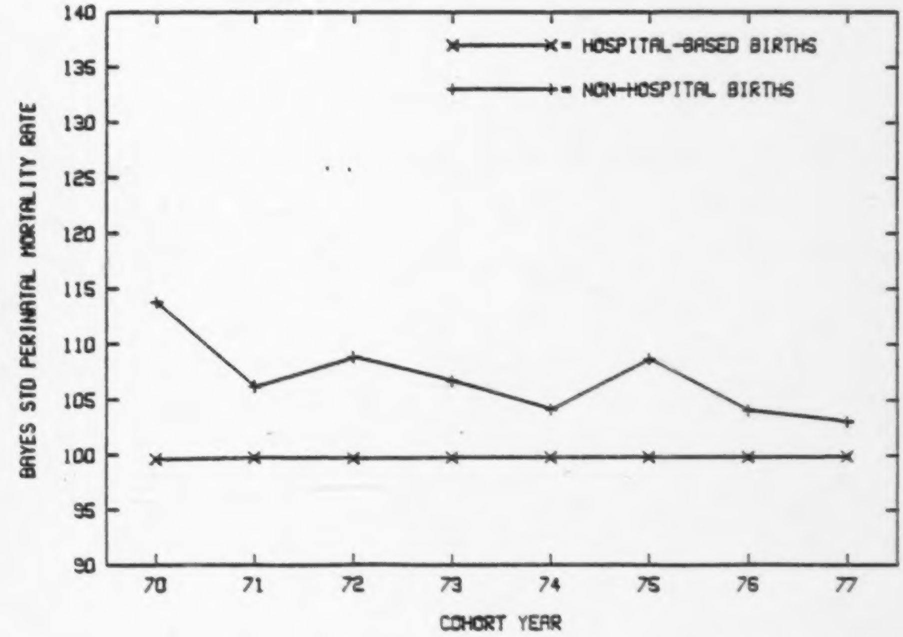

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TABLE 1. POISSON DISTRIBUTION

$$p(x) = \frac{\mu^{x}e^{-\mu}}{x!} \text{ for } \mu = np \text{ and } \pi = .02$$

n = 100 (σ = 14.1)			n = 500 (σ = 6.3)			n = 2000 (σ = 3.2)		
x	p(x)	OBPMR	x	p(x)	OBPMR	x	p(x)	OBPMR
0	.1353	0.0	0	.0000	0.0	0	.0000	0.0
1	.2707	10.0	1	.0004	2.0	↓	↓	
2	.2707	20.0	2	.0023	4.0			
3	.1804	30.0	3	.0076	6.0	19	.0001	9.5
4	.0902	40.0	4	.0189	8.0	20	.0002	10.0
5	.0361	50.0	5	.0378	10.0	21	.0004	10.5
6	.0120	60.0	6	.0630	12.0	22	.0007	11.0
7	.0034	70.0	7	.0901	14.0	23	.0012	11.5
8	.0008	80.0	8	.1126	16.0	24	.0019	12.0
9	.0002	90.0	9	.1251	18.0	25	.0031	12.5
10	.0000	100.0	10	.1251	20.0	26	.0047	13.0
↓	↓		11	.1137	22.2	27	.0070	13.5
			12	.0948	24.0	28	.0100	14.0
∞	.0000		13	.0729	26.0	29	.0138	14.5
			14	.0521	28.0	30	.0185	15.0
			15	.0347	30.0	31	.0238	15.5
			16	.0217	32.0	32	.0298	16.0
			17	.0128	34.0	33	.0361	16.5
			18	.0071	36.0	34	.0425	17.0
			19	.0037	38.0	35	.0485	17.5
			20	.0019	40.0	36	.0539	18.0
			21	.0009	42.0	37	.0583	18.5
			22	.0004	44.0	38	.0614	19.0
			23	.0002	46.0	39	.0629	19.5
			24	.0001	48.0	40	.0629	20.0
			25	.0000	50.0	41	.0614	20.5
			↓	↓		42	.0585	21.0
						43	.0544	21.5
			∞	.0000		44	.0495	22.0
						45	.0440	22.5
						46	.0382	23.0
						47	.0325	23.5
						48	.0271	24.0
						49	.0221	24.5
						50	.0177	25.0
						51	.0139	25.5
						52	.0107	26.0
						53	.0081	26.5
						54	.0060	27.0
						55	.0043	27.5
						56	.0031	28.0
						57	.0022	28.5
						58	.0015	29.0
						59	.0010	29.5
						60	.0007	30.0
						61	.0004	30.5
						62	.0003	31.0
						63	.0000	31.5
						↓	↓	
						∞	.0000	

TABLE 2
NAMES AND DEFINITIONS OF VARIABLES SELECTED FROM THE MATERNAL AND CHILD HEALTH DATA BASE (MCHDB)

Variable No.	Variable Name	Definition
1	BIRTH	Number of births (exclusive of < 501g and unknown birth weights)
2	WHITE	White non-Spanish births (%)
3	SPAN	Spanish-surname births (%)
4	BLACK	Black births (%)
5	OTHER	Births to other races (%)
6	NOPRE	Mothers having no reported prenatal care (%)
7	OUTWED	Out-of-wedlock (inferred) births (%)
8	SHORT	Mothers with short (<17 mo.) interpregnancy interval (%)
9	TEEN	Mothers less than 18 years of age (%)
10	OLDER	Mothers 35 years or older (%)
11	PARA1	Deliveries to primiparas (%)
12	OPARA1	Deliveries to older (35+) primiparas (%)
13	PARA6	Deliveries to grand (>6) multiparas (%)
14	MULT	Multiple births (%)
15	LOBW	Low (<2501 g) birth weight deliveries (%)
16	CSEC	Cesarean sections (%)
17	EXFMR	Expected fetal mortality rate (per 1000)
18	OBFMR	Observed fetal mortality rate (per 1000)
19	ISFMR	Indirectly standardized fetal mortality ratio (%)
20	BSFMR	Bayesian standardized fetal mortality ratio (%)
21	ZFMR	Standardized normal statistic for ISFMR
22	EXNMR	Expected neonatal mortality rate (per 1000)
23	OBNMR	Observed neonatal mortality rate (per 1000)
24	ISNMR	Indirectly standardized neonatal mortality ratio (%)
25	BSNMR	Bayesian standardized neonatal mortality ratio (%)
26	ZNMR	Standard normal statistic for ISNMR
27	EXPMR	Expected perinatal mortality rate (per 1000)
28	OBPMR	Observed perinatal mortality rate (per 1000)
29	ISPMR	Indirectly standardized perinatal mortality ratio (%)
30	BSPMR	Bayesian standardized perinatal mortality ratio (%)
31	ZPMR	Standard normal statistic for ISPMR

TABLE 3
1977 CALIFORNIA BIRTHS BY COUNTY OF RESIDENCE VERSUS COUNTY OF OCCURRENCE*

County	By Residence	By Occurrence	NFB	RI	OI
Alameda	15,600	16,860	+1,260	91.0	84.2
Alpine	16	0	-16	0.0	–
Amador	176	80	-96	36.4	80.0
Butte	1,712	1,716	+4	89.8	89.6
Calaveras	205	92	+113	34.2	76.1
Colusa	214	98	-116	42.5	92.9
Contra Costa	8,192	6,294	-1,898	69.0	89.8
Del Norte	334	329	-15	88.0	89.4
El Dorado	926	676	-250	67.1	91.9
Fresno	8,923	9,064	+141	93.4	91.9
Glenn	344	235	-109	62.5	91.5
Humboldt	1,715	1,751	+36	98.3	96.3
Imperial	1,837	1,887	+50	95.5	93.0
Inyo	234	284	+50	91.0	75.0
Kern	6,846	6,840	-6	94.8	94.9
Kings	1,603	1,764	+161	92.4	84.0
Lake	376	212	-164	55.3	98.1
Lassen	298	161	-137	53.4	98.8
Los Angeles	119,953	124,757	+4,804	97.6	93.8
Madera	991	605	-386	54.5	89.3
Marin	2,213	1,384	-829	51.8	82.8
Mariposa	110	101	-9	69.1	75.2
Mendocino	1,035	1,077	+42	92.4	88.8
Merced	2,520	2,481	-39	87.0	88.4
Modoc	122	59	-63	44.3	91.5
Mono	102	33	-69	31.4	97.0
Monterey	5,560	5,307	-253	93.0	97.4
Napa	1,037	744	-293	61.8	86.2
Nevada	543	640	-97	86.2	73.1
Orange	26,721	24,343	-2,378	82.8	90.9
Placer	1,301	1,162	-139	59.3	66.4
Plumas	242	243	+1	81.4	81.1
Riverside	9,321	8,253	-1,068	77.3	87.3
Sacramento	10,960	11,959	+999	94.2	86.4
San Benito	489	298	-191	57.5	94.3
San Bernardino	13,388	13,361	-27	80.3	80.4
San Diego	26,840	27,281	+441	99.2	97.6
San Francisco	7,928	12,472	+4,544	95.6	60.8
San Joaquin	5,178	5,085	-93	91.6	93.3
San Luis Obispo	1,795	1,695	-100	91.4	96.8
San Mateo	7,265	4,178	-3,087	47.6	82.9
Santa Barbara	3,873	3,958	+85	97.6	95.6
Santa Clara	18,280	19,471	+1,191	94.6	88.8
Santa Cruz	2,515	2,575	+60	89.6	87.5
Shasta	1,518	1,643	+125	97.1	89.7
Sierra	34	22	-12	50.0	77.3
Siskiyou	622	428	-194	67.0	97.4
Solano	3,732	3,842	+110	84.9	82.5
Sonoma	3,851	3,361	-490	84.1	96.3
Stanislaus	4,186	4,576	+390	97.0	88.7
Sutter	784	1,417	+633	86.1	47.6
Tehama	507	443	-64	79.9	91.4
Trinity	163	74	-84	44.2	97.3
Tulare	4,499	4,192	-307	88.2	94.7
Tuolumne	399	455	+56	94.0	82.4
Ventura	8,042	6,749	-1,293	82.0	97.7
Yolo	1,555	1,063	-492	53.6	78.4
Yuba	944	405	-539	36.0	84.0

*NFB = Net Flow of Births
RI = Residence Index
OI = Occurrence Index
(See text for definitions.)

TABLE 4. 1970-1977 California vital record data for HSA 0 (Statewide).

TABLE 4. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 0 (STATEWIDE)
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

HSA:0 HSANAME:ALL_HSAS

COHORT	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	435	362004	64.0	21.2	9.8	4.2	2.5	12.6	16.3	5.9	6.2	41.5	0.5	2.2	2.0	7.5
1971	433	332317	62.0	22.0	9.7	4.6	2.4	12.1	16.2	5.0	5.3	42.1	0.5	2.1	1.9	7.2
1972	425	300027	60.0	24.4	9.7	5.1	2.3	13.1	14.9	6.5	5.4	43.2	0.6	1.9	1.9	7.0
1973	432	300142	58.7	26.5	9.9	5.0	2.6	14.1	14.2	6.6	5.2	44.0	0.6	1.7	1.9	7.3
1974	439	314045	56.3	27.9	10.0	5.3	3.7	14.9	14.0	6.3	5.2	44.0	0.6	1.7	2.0	6.9
1975	407	319737	55.3	28.0	10.2	5.7	3.6	16.7	14.2	6.2	4.9	44.1	0.6	1.6	2.0	6.9
1976	402	334158	53.9	29.0	10.2	6.1	2.9	17.7	14.1	7.9	5.0	44.0	0.4	1.5	2.0	6.8
1977	413	349285	53.6	29.5	10.3	6.6	3.2	18.5	14.1	5.6	5.0	44.3	0.7	1.3	1.9	6.4
TOTAL	503	2622915	58.4	26.3	10.0	5.3	2.9	15.0	14.0	6.1	5.3	43.4	0.6	1.0	2.0	7.0
RANK	15	15	4.0	10.0	12.0	10.0	10.0	12.0	11.0	9.0	11.0	7.0	11.0	9.0	8.3	11.0

COHORT	CSEC	EXPFMR	OBPFMR	ISPFMR	BBPFMR	ZPFMR	EXNMR	OBNMR	ISNMR	BBNMR	ZNMR	EXPMR	OBPMR	ISPMR	BBPMR	ZPMR
1970	6.9	10.0	10.0	100.0	100.0	0.0	11.4	11.4	100.0	100.0	0.0	21.3	21.3	100.0	100.0	0.0
1971	7.6	9.4	9.4	100.0	100.0	0.0	10.7	10.7	100.0	100.0	0.0	20.3	20.3	100.0	100.0	0.0
1972	8.7	9.0	9.0	100.0	100.0	0.0	10.3	10.3	100.0	100.0	0.0	19.2	19.2	100.0	100.0	0.0
1973	9.3	8.0	8.0	100.0	100.0	0.0	9.2	9.2	100.0	100.0	0.0	17.9	17.9	100.0	100.0	0.0
1974	11.3	8.3	8.0	100.0	100.0	0.0	8.3	8.3	100.0	100.0	0.0	17.0	17.0	100.0	100.0	0.0
1975	12.3	8.1	8.0	100.0	100.0	0.0	7.8	7.9	100.0	100.0	0.0	15.8	15.8	100.0	100.0	0.0
1976	14.8	8.1	8.1	100.0	100.0	0.0	7.3	7.3	100.0	100.0	0.0	15.4	15.4	100.0	100.0	0.0
1977	15.4	7.5	7.5	100.0	100.0	0.0	6.0	6.0	100.0	100.0	0.0	14.2	14.2	100.0	100.0	0.0
TOTAL	10.5	8.7	8.7	100.0	100.0	0.0	9.0	9.2	100.0	100.0	0.0	17.6	17.6	100.0	100.0	0.0
RANK	9.3	10.0	11.0	10.0	10.0	10.0	7.0	11.0	7.0	7.0	7.0	11.0	12.0	9.0	8.0	8.0

TABLE 5. 1970-1977 California vital record data by HSA of occurrence.

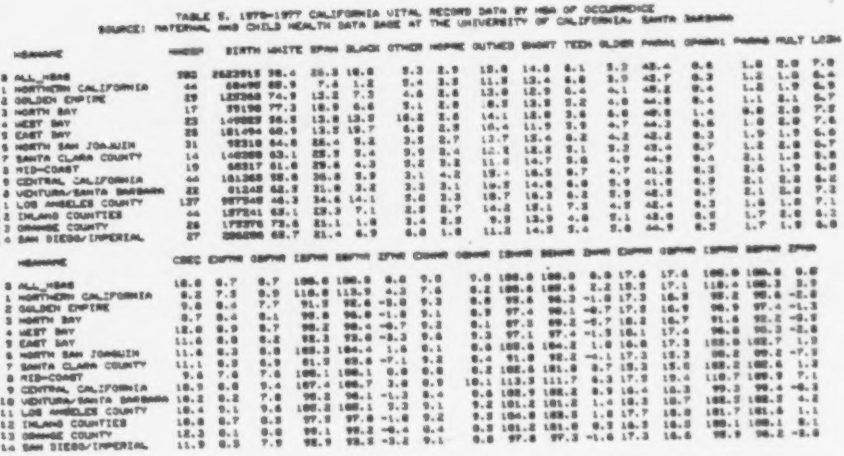

TABLE 5. 1970-1977 CALIFORNIA VITAL RECORD DATA BY HSA OF OCCURRENCE
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

TABLE 6. 1970-1977 California vital record data for HSA 5 by place of occurrence.

TABLE 6. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 5 BY OCCURRENCE
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

HSA=5 HSANAME=EAST BAY

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	26424	65.2	12.6	17.5	4.7	1.5	13.9	13.4	6.2	5.2	42.8	0.5	1.4	2.2	7.9
1971	24288	64.6	12.0	18.2	5.0	1.9	14.0	13.1	5.9	5.0	42.9	0.5	1.3	1.9	7.6
1972	22409	62.5	13.4	18.8	5.4	1.8	14.6	11.9	6.6	4.8	43.7	0.6	1.1	2.1	7.7
1973	20739	61.3	13.6	19.8	5.4	1.6	15.4	11.2	6.2	4.7	44.1	0.6	0.9	1.8	7.5
1974	21106	60.0	13.9	20.3	5.8	3.7	16.6	11.1	6.1	4.4	45.1	0.7	0.9	2.1	7.7
1975	21170	59.1	13.8	20.7	6.4	5.4	18.1	11.6	5.8	4.3	45.3	0.6	0.7	2.0	7.6
1976	22155	57.3	13.9	21.4	7.5	2.1	19.0	11.5	5.1	4.6	45.1	0.7	0.7	2.1	7.7
1977	23103	56.6	14.1	21.6	7.7	2.1	20.3	11.2	5.1	4.8	46.1	0.8	0.6	1.7	7.1
TOTAL	181494	60.9	13.5	19.7	6.0	2.5	16.4	11.9	5.9	4.7	44.3	0.6	1.0	2.0	7.6
RANK	12	5.0	4.0	15.0	13.0	4.0	14.0	1.0	7.0	7.0	16.0	12.0	2.0	11.0	15.0

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	7.3	10.2	9.0	88.9	92.9	-2.0	12.1	12.8	98.6	99.0	-0.3	21.9	20.9	95.3	98.5	-1.4
1971	8.3	9.7	9.4	96.9	98.1	-0.5	11.4	12.4	100.3	100.7	1.7	20.7	21.7	104.0	103.5	1.4
1972	9.0	9.3	8.6	92.0	98.4	-1.3	11.3	11.1	98.6	99.1	-0.3	20.4	19.6	96.2	97.3	-1.8
1973	10.9	8.5	7.2	84.1	91.5	-2.3	9.5	9.2	96.7	98.1	-0.6	17.5	16.3	93.1	95.5	-1.6
1974	12.5	9.0	7.7	88.7	92.0	-2.2	8.7	8.2	94.1	98.6	-1.0	17.4	15.9	91.3	94.3	-2.1
1975	14.5	7.9	8.0	101.5	100.0	0.2	8.1	8.7	88.0	98.1	-2.8	16.2	14.6	90.3	93.8	-2.2
1976	15.2	8.4	8.3	90.7	99.3	-0.2	8.1	7.6	94.5	98.8	-0.9	16.1	15.9	98.6	99.1	-0.3
1977	16.6	7.4	6.8	91.8	98.7	-1.1	6.9	6.6	95.3	97.6	-0.7	14.0	13.3	95.5	97.2	-1.8
TOTAL	11.6	8.8	8.2	92.3	93.8	-3.3	9.6	9.3	97.1	97.4	-1.5	18.1	17.4	96.8	98.3	-2.0
RANK	11.0	13.0	8.0	3.0	3.3	2.0	15.0	13.0	5.0	5.0	5.0	13.0	11.0	5.3	5.8	4.0

TABLE 7. 1970-1977 California vital record data for HSA 5 by county of occurrence.

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                 TABLE 7. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 5 BY COUNTY OF OCCURRENCE
            SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

 ------------------------------ CNTY=1   COUNTY=ALAMEDA   HSA=5   HSANAME=EAST BAY ------------------------------

COHORT NHOSP  BIRTH WHITE SPAN BLACK OTHER NOPRE OUTWED SHORT TEEN OLDER PARA1 OPARA1 PARA6 MULT LOBW

1970    15    18900 61.2  13.0  20.2   5.5   1.0  14.0   14.1   5.9   5.3 44.0    0.6    1.5  2.3  8.2
1971    14    17520 59.5  13.6  21.0   5.9   2.3  15.1   13.5   5.8   5.3 44.0    0.6    1.3  2.0  7.8
1972    15    16004 57.3  14.3  21.9   6.5   2.2  15.7   12.6   6.3   4.9 44.6    0.7    1.2  2.2  8.2
1973    14    14922 56.4  14.5  22.8   6.3   1.9  16.5   11.9   6.1   4.8 44.9    0.6    0.9  1.8  7.9
1974    15    15307 55.1  14.6  23.5   6.8   4.7  17.9   11.4   6.3   4.5 45.0    0.7    0.9  2.1  8.0
1975    15    15207 53.7  14.5  24.2   7.6   6.6  19.0   12.3   5.9   4.4 46.4    0.7    0.7  2.1  8.1
1976    14    16125 51.4  14.4  25.3   8.7   1.9  21.3   11.7   5.2   4.9 45.7    0.8    0.7  2.2  8.3
1977    15    16018 50.5  14.4  26.1   8.9   1.7  23.0   11.5   5.4   4.9 46.0    0.9    0.6  1.8  7.7
TOTAL   17   130909 55.0  14.1  23.1   7.0   2.8  17.9   12.4   5.9   4.9 45.2    0.7    1.0  2.1  8.0
PRCNTL   .       92 16.9  52.5 100.0  83.1  38.8  96.6   15.3  37.3  59.3 76.3   93.2   27.1 83.1 93.2

COHORT CSEC [illegible] OBFHR ISFHR BBFHR ZFHR EXHWR OBHWR ISHWR BBHWR ZHWR EXPHR OBPHR ISPHR BBPHR ZPHR

1970    7.0 10.5    9.1  87.0  89.0  -2.0  12.7  11.0   92.9  96.0 -1.4 22.6  20.0   92.2  93.0 -2.1
1971    8.1  9.9    9.3  94.1  95.5  -0.0  11.9  12.3  102.0 101.6  0.6 21.1  21.5  101.0 101.4  0.4
1972    9.0  9.6    8.4  87.5  90.8  -1.7  12.0  11.6   96.6  98.3 -0.6 21.2  19.9   94.0  95.5 -1.4
1973   10.3  8.8    7.0  79.9  85.0  -2.5   9.9   9.4   95.0  98.2 -0.6 18.1  16.4   90.9  93.7 -1.0
1974   12.2  9.2    7.7  83.0  88.3  -2.1   9.2   8.7   94.0  97.5 -0.9 17.9  16.3   91.1  93.7 -1.5
1975   13.0  8.4    8.0  95.3  96.7  -0.6   8.0   6.9   78.6  91.6 -5.0 17.2  14.9   86.6  90.7 -2.7
1976   14.0  9.1    8.7  96.5  97.5  -0.5   8.9   8.5   93.1  97.9 -0.7 17.5  17.2   98.0  98.6 -0.4
1977   16.2  8.1    7.4  92.3  94.5  -1.0   7.6   7.0   91.7  96.0 -1.1 15.3  14.4   93.9  95.0 -1.2
TOTAL  11.3  9.2    8.3  89.6  90.4  -3.9  10.2   9.6   94.1  94.9 -2.7 19.0  17.0   93.9  94.3 -3.9
PRCNTL 81.4 93.2   58.0  18.6   6.8   3.4  93.2  79.7   28.0   5.1  5.1 89.0  69.5   22.0  10.2  5.1

 ------------------------------ CNTY=7   COUNTY=CONTRA COSTA   HSA=5   HSANAME=EAST BAY ------------------------------

COHORT NHOSP BIRTH WHITE SPAN BLACK OTHER NOPRE OUTWED SHORT TEEN OLDER PARA1 OPARA1 PARA6 MULT LOBW

1970     8    7436 75.6  11.3 10.5    2.6   0.9  11.7   11.9   6.9   4.0 39.9    0.3    1.2  1.9  7.1
1971     9    6732 75.6  10.7 11.1    2.6   0.8  11.1   11.9   6.2   4.9 40.0    0.3    1.1  1.7  7.0
1972     8    6405 75.4  11.8 11.1    2.5   0.6  11.9   10.1   7.2   4.3 41.5    0.3    0.8  1.8  6.5
1973     9    5837 73.9  11.2 12.1    2.9   0.0  12.8    9.4   6.4   4.2 42.1    0.7    0.6  1.8  6.6
1974     8    5879 72.9  12.1 11.8    3.2   1.1  13.2   10.4   5.4   4.2 43.1    0.5    0.8  2.0  6.9
1975     8    5971 72.8  12.0 11.7    3.5   2.3  13.5   10.1   5.6   4.1 42.6    0.5    0.7  1.7  6.3
1976     8    6020 73.2  12.3 10.2    4.3   2.6  12.9   10.9   4.8   3.9 43.5    0.6    0.7  2.0  6.2
1977     8    6285 72.7  13.4  9.4    4.5   3.2  13.2   10.6   4.2   4.5 44.5    0.7    0.7  1.5  5.6
TOTAL    9   50565 74.1  11.7 11.0    3.2   1.5  12.5   10.7   5.9   4.4 42.0    0.5    0.9  1.8  6.5
PRCNTL   .      81 49.2  44.1 93.2   42.4  15.3  64.4    6.8  39.8  58.0 28.0   79.7   15.3 32.2 53.9

COHORT CSEC EXFHR OBFHR ISFHR BBFHR ZFHR EXHWR OBHWR ISHWR BBHWR ZHWR EXPHR OBPHR ISPHR BBPHR ZPHR

1970    8.3   9.4   8.9  94.4  96.9 -0.5  10.7  12.3  115.0 104.4  1.7 20.2  21.1  104.4 102.5  0.7
1971    8.7   9.2   9.6 104.5 102.4  0.4  10.2  12.7  124.4 106.2  2.3 19.6  22.2  113.2 107.1  1.9
1972    9.1   8.5   8.9 104.0 102.4  0.4   9.5   9.9  104.9 101.1  0.5 18.3  18.7  102.6 101.3  0.4
1973   12.3   7.0   7.5  96.4  98.4 -0.3   8.5   8.5   99.5  99.9 -0.0 16.2  15.9   99.4  99.7 -0.1
1974   13.3   8.4   7.7  91.0  95.7 -0.7   7.4   7.0   94.6  99.1 -0.4 15.9  14.6   92.2  96.6 -0.9
1975   14.6   6.6   8.0 121.6 109.0  1.5   6.5   6.1   93.9  99.2 -0.4 13.0  14.1  102.2 100.9  0.2
1976   16.3   6.7   7.1 100.4 102.7  0.4   5.0   5.4   91.9  98.9 -0.6 12.4  12.5  100.6 100.2  0.1
1977   17.6   5.7   5.1  90.1  96.2 -0.6   4.9   5.4  111.1 101.3  0.7 10.3  10.5  101.7 100.5  0.2
TOTAL  12.3   7.0   7.9 100.7 100.6  0.2   8.0   8.6  106.9 104.4  1.7 16.2  16.4  102.0 102.3  1.0
PRCNTL 93.2  47.5  39.0  39.0  45.0 42.4  42.4  59.3   67.0  89.0 84.7 42.4  40.7   50.0  64.4 61.2
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TABLE 8. 1970-1977 California vital record data for HSA 5 by county of residence.

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              TABLE 8. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 5 BY COUNTY OF RESIDENCE
         SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

------------------------ RES=1   COUNTY=ALAMEDA   HSA=5   HSANAME=EAST BAY ------------------------

COHORT  BIRTH WHITE SPAN BLACK OTHER NOPRE OUTWED SHORT TEEN OLDER PARA1 OPARA1 PARA6 MULT LOBW

1970    18485 60.9  13.3  20.2   5.6   1.8  15.2  14.3   6.8   5.1 44.5    0.5    1.4  2.4  8.2
1971    16846 58.9  14.0  21.1   6.1   2.2  15.5  13.7   5.9   4.8 44.9    0.6    1.3  1.9  7.7
1972    15309 57.3  14.7  21.7   6.2   2.2  16.0  12.7   6.4   4.6 45.4    0.7    1.1  2.1  8.1
1973    14281 55.9  14.8  22.8   6.5   1.9  17.8  12.0   6.2   4.8 45.3    0.6    1.0  1.7  7.8
1974    14550 54.9  14.8  23.4   7.0   4.5  18.4  11.3   6.4   4.3 46.3    0.7    0.9  2.0  8.0
1975    14394 53.7  14.7  23.8   7.8   6.3  20.0  12.2   5.9   4.4 46.4    0.7    0.7  2.1  7.9
1976    14692 50.7  14.9  25.4   9.0   1.8  21.7  11.8   5.1   4.7 45.9    0.8    0.7  2.0  7.9
1977    15556 50.1  15.0  25.7   9.1   2.0  23.2  11.6   5.3   4.9 46.7    0.9    0.7  1.8  7.6
TOTAL  124285 55.5  14.5  22.9   7.1   2.6  18.3  12.5   5.9   4.7 45.6    0.7    1.0  2.0  7.9
PRCNTL     93 15.5  53.4 100.0  84.5  55.2  96.6  15.5  41.4  63.0 86.2   91.4   25.9 75.9 93.1

COHORT CSEC EXFMR OBFMR ISFMR BSFMR ZFMR EXNMR OBNMR ISNMR BSNMR ZNMR EXPMR OBPMR ISPMR BSPMR ZPMR

1970    6.9 10.2    9.3  88.9  91.3 -1.7 12.6  11.9   94.8  97.1 -1.0 22.5  21.1   93.8  95.1 -1.6
1971    8.1  9.9    9.8  98.5  98.9 -1.3 12.0  12.2  101.9 101.0  0.3 21.8  21.1  100.3 100.2  0.1
1972    8.9  9.6    8.5  88.1  91.3 -1.6 12.0  11.4   95.2  97.6 -0.8 21.2  19.8   93.5  95.2 -1.5
1973   10.6  9.8    7.8  86.0  90.7 -1.6 10.1   9.2   91.6  96.5 -1.3 18.6  17.0   91.7  94.2 -1.7
1974   12.5  9.3    7.8  83.4  88.1 -2.1  9.3   8.9   95.4  98.1 -0.7 18.1  16.6   91.6  94.1 -1.7
1975   14.1  8.4    8.3  99.0  99.3 -0.1  8.5   7.0   82.1  93.4 -2.4 17.1  15.3   89.4  92.8 -2.1
1976   15.1  8.5    8.1  95.6  96.9 -0.5  8.1   7.4   90.9  96.5 -1.3 16.1  15.4   96.1  97.4 -0.8
1977   16.5  7.8    7.4  94.7  96.3 -0.6  7.3   6.7   91.9  97.2 -1.0 14.8  14.0   94.9  96.6 -1.0
TOTAL  11.4  9.2    8.3  90.6  91.4 -3.5 10.1   9.5   93.0  94.7 -2.8 18.8  17.7   94.1  94.6 -3.6
PRCNTL 86.2 94.8   56.9  29.3  10.3  6.9 93.1  79.3   29.3   6.9  5.2 91.4  62.1   27.6   6.9  5.2

------------------------ RES=7   COUNTY=CONTRA COSTA   HSA=5   HSANAME=EAST BAY ------------------------

COHORT  BIRTH WHITE SPAN BLACK OTHER NOPRE OUTWED SHORT TEEN OLDER PARA1 OPARA1 PARA6 MULT LOBW

1970     8898 75.4  10.6  10.9   3.1   0.9  10.7  11.8   6.3   5.8 40.3    0.4    1.3  1.7  7.8
1971     8091 74.9  10.2  11.8   3.1   0.9  10.1  11.8   5.6   5.4 39.8    0.4    1.1  1.8  6.9
1972     7702 73.6  10.5  12.6   3.3   0.9  11.2  10.2   6.5   5.8 41.5    0.4    0.9  2.1  6.7
1973     7012 72.5  10.5  13.2   3.8   0.9  11.7   9.4   5.6   4.5 42.3    0.7    0.6  1.6  6.4
1974     7185 70.9  11.5  13.5   4.1   1.7  12.7  10.4   5.4   4.6 44.2    0.7    0.8  2.2  7.4
1975     7419 70.8  11.6  14.8   4.5   3.1  13.4  10.5   5.3   4.1 44.1    0.5    0.6  1.6  6.7
1976     7674 70.1  11.5  13.5   5.0   2.4  13.8  10.6   4.7   4.6 43.8    0.8    0.6  2.3  7.8
1977     8177 68.5  12.3  13.5   5.7   2.0  14.6  10.5   4.5   5.0 45.6    0.9    0.5  1.7  6.5
TOTAL   62158 72.1  11.1  12.8   4.0   1.7  12.3  10.7   5.5   4.8 42.6    0.6    0.8  1.9  6.8
PRCNTL     83 44.8  44.8  93.1  51.7  13.8  69.0   3.4  31.0  67.2 34.5   87.9   13.8 37.9 69.0

COHORT CSEC EXFMR OBFMR ISFMR BSFMR ZFMR EXNMR OBNMR ISNMR BSNMR ZNMR EXPMR OBPMR ISPMR BSPMR ZPMR

1970    7.8  9.4    8.8  93.6  96.1 -0.6 10.7  11.2  105.3 101.7  0.6 20.0  19.9   99.4  99.6 -0.1
1971    8.8  9.8   10.4 115.3 108.7  1.4  9.9  11.4  114.9 104.1  1.6 19.2  21.6  112.7 107.2  2.0
1972    9.5  8.7    8.6  99.0  99.5 -0.1  9.9  10.2  102.0 100.8  0.3 18.7  18.7  100.0 100.0  0.0
1973   11.6  7.7    6.7  87.3  93.7 -1.0  8.2   8.3  101.5 100.3  0.1 15.6  15.0   96.3  98.3 -0.5
1974   12.9  9.1    8.4  92.2  95.7 -0.7  8.4   8.1   96.4  99.2 -0.3 17.5  16.4   93.7  96.7 -0.9
1975   14.2  7.4    8.4 113.3 106.0  1.1  7.5   6.4   84.8  97.8 -1.3 15.3  14.7   95.9  98.4 -0.5
1976   15.7  8.5    8.6 101.4 100.8  0.1  8.2   6.7   82.1  95.6 -1.8 16.4  15.2   93.2  96.4 -1.0
1977   16.7  6.9    5.6  81.7  90.8 -1.5  6.7   6.3   94.8  98.8 -0.5 13.8  11.9   91.2  96.8 -1.1
TOTAL  12.1  8.3    8.2  98.3  98.6 -0.4  8.7   8.6   99.8  99.3 -0.3 17.8  16.8   98.5  98.7 -0.6
PRCNTL 91.4 62.1   53.4  48.3  39.7 39.7 55.2  56.9   48.3  44.8 44.8 55.2  46.6   46.6  37.9 34.5
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TABLE 9. 1970-1977 California vital record data for HSA 5 by HFPA of occurrence.

TABLE 9. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 5 BY HFPA OF OCCURRENCE
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

HFPA=411 HFPANAME=CONCORD COUNTY=CONTRA COSTA HSANAME=EAST BAY

COHORT	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	6	4784	83.7	10.7	3.1	2.5	0.7	6.9	10.4	4.8	5.3	37.9	0.1	0.9	2.0	6.4
1971	7	4999	81.0	11.1	5.2	2.7	0.8	7.5	11.1	4.9	5.2	39.5	0.3	1.0	1.6	6.3
1972	6	4800	81.4	10.8	5.1	2.7	0.7	7.9	10.2	5.7	4.4	41.0	0.4	0.7	1.7	5.0
1973	7	4435	80.3	10.9	5.7	3.1	0.7	8.3	8.8	4.9	4.4	41.8	0.7	0.5	1.7	5.6
1974	6	4564	79.4	12.2	5.0	3.4	1.0	8.5	10.3	4.3	4.4	42.0	0.5	0.8	2.0	6.4
1975	6	4721	78.4	12.1	6.0	3.5	2.6	9.0	9.4	4.5	4.4	42.0	0.5	0.6	1.6	5.9
1976	6	4981	78.0	11.9	5.6	4.5	2.7	9.4	10.3	3.8	4.1	43.6	0.6	0.7	2.1	5.3
1977	6	5297	77.3	13.0	5.1	4.6	3.4	10.3	10.3	3.7	4.7	44.0	0.7	0.6	1.4	5.0
TOTAL	7	38689	79.9	11.6	5.1	3.4	1.6	8.5	10.1	4.6	4.7	41.7	0.5	0.7	1.8	5.8
PRCNTL	.	86	65.3	42.2	62.6	44.2	30.1	26.5	3.4	22.4	51.7	34.7	76.2	15.6	32.7	25.9

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	9.4	8.8	8.4	94.5	97.0	-0.4	9.5	11.2	117.3	105.5	1.4	19.1	19.4	101.7	101.3	0.2
1971	9.9	8.4	9.3	106.6	103.6	0.5	9.1	10.9	120.4	106.3	1.6	17.9	19.0	110.5	105.0	1.2
1972	10.4	8.8	6.9	86.3	92.0	-0.9	8.6	8.8	92.1	97.6	-0.6	16.3	14.8	87.4	93.2	-1.4
1973	13.9	7.1	7.4	104.5	102.1	0.3	7.6	8.1	107.0	101.0	0.5	14.4	15.5	107.3	103.3	0.7
1974	15.3	8.1	7.4	92.0	95.9	-0.5	6.0	6.2	90.4	97.0	-0.6	13.2	13.6	89.3	94.9	-1.1
1975	17.3	6.5	7.8	121.0	109.7	1.2	6.3	5.6	88.7	97.7	-0.7	13.6	13.3	90.3	99.2	-0.2
1976	18.4	5.8	6.2	107.0	103.1	0.4	4.9	4.6	94.8	99.0	-0.3	10.7	10.0	101.3	100.3	0.1
1977	19.6	5.2	5.3	101.3	100.6	0.1	4.2	5.5	129.0	104.0	1.5	9.4	10.0	114.3	105.2	1.1
TOTAL	14.3	7.2	7.3	100.9	100.7	0.2	7.1	7.5	105.3	103.9	1.1	14.6	14.7	100.0	100.7	0.2
PRCNTL	95.9	22.4	32.0	50.3	54.4	51.7	15.6	21.0	57.1	76.9	78.7	23.0	25.2	43.5	46.3	46.3

HFPA=413 HFPANAME=RICHMOND COUNTY=CONTRA COSTA HSANAME=EAST BAY

COHORT	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	2	2624	60.7	12.5	24.0	2.7	1.3	20.7	14.0	10.7	3.4	43.0	0.4	1.0	1.6	8.8
1971	2	1731	60.3	9.5	28.0	2.2	0.7	21.1	13.9	10.0	4.2	41.0	0.3	1.3	1.0	8.9
1972	2	1571	56.9	11.7	29.2	2.2	0.0	24.0	9.0	11.0	3.9	42.6	0.3	1.1	1.9	8.3
1973	2	1362	52.8	12.2	32.8	2.1	0.7	27.3	10.0	11.3	3.5	43.2	0.4	1.0	1.9	9.6
1974	2	1276	49.6	11.9	36.0	2.6	1.2	29.2	11.5	9.1	3.2	44.5	0.5	0.9	2.0	8.8
1975	2	1215	50.8	11.9	33.9	3.4	0.5	30.4	12.0	9.7	3.3	44.0	0.6	1.1	2.1	8.3
1976	2	998	48.8	14.4	33.7	3.0	1.0	30.7	13.3	9.4	3.0	43.4	0.5	0.5	1.4	11.1
1977	2	929	46.7	15.7	33.8	3.9	1.7	29.0	12.3	7.4	3.0	43.0	0.6	1.0	2.4	8.9
TOTAL	2	11706	54.9	12.2	30.3	2.7	1.0	25.9	12.6	10.2	3.6	43.4	0.4	1.2	1.9	8.8
PRCNTL	.	44	21.1	44.9	97.3	27.9	15.6	97.3	26.5	92.3	15.6	93.1	63.3	42.2	46.3	95.9

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	5.5	10.0	8.0	87.5	94.7	-0.7	11.9	13.3	113.4	103.3	0.9	20.9	22.1	105.6	102.4	0.5
1971	5.3	10.0	11.6	107.1	102.5	0.3	12.3	16.9	137.4	107.1	2.2	23.2	20.3	122.3	100.3	1.0
1972	5.1	9.7	14.0	144.5	112.4	1.9	11.3	14.2	125.4	104.3	1.4	21.3	20.0	131.6	110.3	2.3
1973	7.2	9.9	7.3	73.9	92.0	-1.0	11.0	8.9	88.7	97.4	-0.9	20.6	16.2	78.3	94.0	-1.4
1974	6.7	9.3	7.8	84.1	96.0	-0.6	9.5	10.3	100.4	101.8	0.4	17.9	18.0	100.4	100.1	3.0
1975	5.7	7.0	8.2	117.6	103.2	0.5	7.2	8.3	115.0	101.1	0.5	14.1	16.5	116.7	102.0	0.8
1976	6.7	11.3	11.1	90.2	99.5	-0.1	10.6	9.2	87.0	98.5	-0.6	21.0	20.2	95.9	99.3	-0.2
1977	7.1	7.9	4.3	54.0	92.5	-1.3	7.7	4.3	56.3	97.1	-1.4	14.9	8.6	57.9	93.8	-1.0
TOTAL	6.8	9.6	9.4	97.7	98.6	-0.3	10.6	11.6	109.4	105.1	1.3	19.0	20.9	105.5	103.5	1.0
PRCNTL	10.9	92.3	75.3	44.2	42.2	44.2	91.0	89.0	66.7	85.0	76.2	92.3	89.0	61.2	71.4	63.3

HFPA=415 HFPANAME=BERKELEY COUNTY=ALAMEDA HSANAME=EAST BAY

COHORT	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	1	2250	56.1	4.9	33.3	5.7	1.3	22.7	11.6	4.0	6.2	50.1	1.1	1.6	2.3	7.6
1971	1	2151	50.9	4.6	39.6	5.0	1.4	26.6	12.3	6.0	5.3	49.3	0.8	1.1	2.0	8.3
1972	1	2077	43.9	4.5	46.3	5.3	1.6	29.7	10.9	6.3	5.2	47.0	1.2	1.4	2.5	8.9
1973	1	1852	42.5	4.1	47.8	5.6	0.9	31.3	10.0	7.2	5.6	47.5	1.0	0.5	1.9	9.0
1974	1	2030	40.6	5.9	48.8	4.7	0.9	34.7	9.7	8.5	5.5	48.9	1.0	0.8	1.9	9.6
1975	1	2160	40.9	7.9	46.2	4.9	12.3	35.3	11.1	6.4	4.0	50.7	0.9	0.4	1.0	8.4
1976	1	2360	38.7	7.3	49.1	4.9	0.7	35.9	11.0	6.0	5.3	48.7	1.1	0.7	2.2	9.1
1977	1	2693	39.6	7.0	48.1	5.2	0.4	38.2	10.3	6.2	5.7	49.5	1.5	0.6	1.5	9.7
TOTAL	1	17629	44.3	5.9	44.9	5.2	3.3	32.0	10.9	6.4	5.3	49.1	1.1	0.8	2.1	8.9
PRCNTL	.	71	10.2	12.2	100.0	66.7	76.2	98.6	10.2	51.7	60.7	89.0	96.6	21.0	77.6	96.6

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	9.6	9.8	10.2	104.7	101.0	0.2	11.6	8.1	60.0	93.3	-1.9	20.5	18.2	80.2	95.6	-0.9
1971	11.0	10.3	9.0	94.7	98.0	-0.3	12.2	9.4	77.8	94.7	-1.5	21.9	19.1	87.8	94.8	-1.1
1972	11.7	9.4	8.7	92.6	97.3	-0.4	10.5	6.8	64.0	93.5	-2.8	19.6	15.4	70.6	92.3	-1.7
1973	12.7	8.6	7.9	91.0	97.5	-0.4	9.7	8.5	87.9	98.2	-0.6	17.9	16.4	91.3	97.4	-0.6
1974	13.1	10.0	9.8	97.0	99.2	-0.1	9.7	10.9	112.4	102.1	0.7	19.4	20.6	106.4	102.3	0.5
1975	14.6	9.6	9.7	101.3	100.5	0.1	9.1	5.1	58.7	92.2	-2.4	19.8	14.0	77.9	91.2	-1.9
1976	16.4	9.1	8.9	97.6	99.1	-0.1	9.8	7.7	85.1	97.2	-0.9	17.7	16.5	93.2	97.5	-0.6
1977	15.0	9.2	8.9	97.1	98.8	-0.2	9.4	6.8	64.1	92.2	-2.3	17.8	14.9	83.4	93.3	-1.4
TOTAL	13.2	9.5	9.2	97.4	98.2	-0.4	10.1	7.7	76.4	85.2	-3.9	19.2	16.9	88.1	91.4	-2.7
PRCNTL	98.5	91.2	74.1	43.5	39.5	42.9	87.1	38.6	4.1	0.7	1.4	84.4	52.4	12.9	4.8	6.1

TABLE 9. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 5 BY HFPA OF OCCURRENCE
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

——— HFPA=417 HFPANAME=OAKLAND COUNTY=ALAMEDA HSANAME=EAST BAY ———

COHORT	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	7	7053	48.1	12.3	31.1	8.4	2.8	18.9	14.9	7.8	5.2	44.3	0.4	1.7	2.5	9.2
1971	6	5868	45.3	12.9	32.5	9.3	3.5	18.9	14.6	6.7	5.6	45.4	0.9	1.5	1.8	8.6
1972	7	5211	44.8	12.9	31.6	10.7	3.6	19.4	13.3	6.9	5.3	45.8	0.9	1.5	2.1	9.5
1973	6	4737	42.7	13.9	34.0	9.4	3.1	19.6	14.8	6.2	5.1	46.2	0.8	0.9	2.1	8.9
1974	7	4729	40.7	14.1	34.2	10.9	3.5	21.0	12.5	6.5	5.1	47.7	1.2	1.1	2.0	8.8
1975	6	4737	39.6	13.4	35.6	11.4	4.1	23.1	14.5	6.4	5.4	47.7	0.9	0.8	2.4	9.1
1976	6	4822	36.7	12.9	38.2	12.2	3.7	26.2	13.8	5.5	6.1	46.1	1.2	1.3	2.4	9.7
1977	7	4955	34.6	12.8	40.1	12.4	3.8	28.0	12.4	5.4	5.5	48.2	1.1	0.9	1.8	8.2
TOTAL	8	42112	42.0	13.1	34.4	10.5	3.3	21.7	13.8	6.4	5.4	46.3	0.9	1.2	2.1	9.0
PRCNTL	.	89	9.5	46.3	98.8	93.5	75.9	94.6	42.9	51.8	72.1	76.9	93.2	46.9	84.4	97.3

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BBFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	6.9	11.6	10.2	87.9	91.5	-1.2	14.2	13.2	92.8	96.0	-0.9	25.0	23.3	92.9	94.8	-1.2
1971	7.9	11.4	10.6	93.8	95.4	-0.6	13.6	14.8	100.8	104.3	1.0	24.0	25.2	103.2	103.5	0.8
1972	9.2	11.4	10.4	91.1	94.3	-0.8	14.8	13.8	98.6	99.3	-0.2	25.8	24.0	98.1	97.3	-0.6
1973	10.6	9.3	7.0	75.3	86.4	-1.8	10.1	11.3	112.1	104.0	1.0	19.9	18.2	95.4	97.5	-0.5
1974	11.5	9.4	5.5	58.5	76.7	-3.0	10.1	8.7	85.1	98.1	-1.2	18.4	14.2	78.9	87.3	-2.7
1975	13.8	9.1	8.7	95.4	97.5	-0.3	9.7	7.5	76.5	92.1	-2.0	18.3	16.8	87.8	93.3	-1.4
1976	14.3	10.3	9.7	94.5	96.7	-0.4	10.3	9.6	93.3	97.5	-0.6	20.1	19.3	95.6	97.5	-0.5
1977	14.8	8.8	8.3	93.9	96.6	-0.4	8.1	7.9	98.4	99.5	-0.1	16.6	16.1	97.3	98.5	-0.3
TOTAL	10.7	10.3	8.9	86.9	88.8	-3.8	11.5	11.1	96.5	97.1	-1.0	21.1	19.9	94.2	94.9	-2.2
PRCNTL	61.9	98.2	60.7	28.5	8.8	4.8	97.3	83.8	33.3	17.7	17.7	97.3	83.7	24.5	13.6	8.8

——— HFPA=419 HFPANAME=LIVERMORE COUNTY=ALAMEDA HSANAME=EAST BAY ———

COHORT	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	1	671	87.4	9.6	0.7	2.2	0.3	5.4	9.5	3.3	7.8	34.2	0.9	1.0	0.9	4.8
1971	1	660	85.1	10.7	0.9	3.3	0.9	5.6	11.1	3.3	5.1	34.9	0.3	0.9	1.0	4.8
1972	1	646	86.0	9.7	1.2	3.1	1.1	4.3	8.4	3.2	6.2	34.8	0.5	0.9	1.9	5.6
1973	1	673	84.6	10.5	1.0	3.8	1.2	5.2	9.8	5.2	6.5	34.4	0.7	0.4	0.6	4.5
1974	1	669	86.8	7.3	1.3	4.6	1.3	4.6	6.8	4.0	5.5	36.9	0.1	0.7	2.1	5.8
1975	1	762	86.1	9.0	1.0	3.8	0.9	7.5	9.5	4.7	4.5	39.4	0.3	0.8	1.3	5.5
1976	1	691	82.7	11.4	1.3	4.6	1.2	9.4	9.8	5.2	3.9	41.2	0.4	1.0	1.2	5.1
1977	1	775	83.2	11.5	1.3	4.0	0.6	10.5	9.0	3.6	6.2	42.7	0.5	0.8	2.1	4.6
TOTAL	1	5547	85.2	10.1	1.1	3.6	0.9	6.7	9.1	4.1	5.6	37.4	0.5	0.9	1.5	5.0
PRCNTL	.	43	88.3	36.1	32.0	50.3	14.3	16.3	1.4	15.6	76.9	4.0	70.1	26.5	11.6	6.0

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BBFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	7.6	8.0	4.5	55.7	93.0	-1.1	10.1	9.8	89.2	99.0	-0.4	16.3	13.4	82.2	97.4	-0.8
1971	9.2	7.0	7.6	107.6	100.9	0.2	9.6	9.2	95.0	99.7	-0.1	16.3	16.7	102.5	100.3	0.1
1972	8.6	5.8	4.6	73.7	98.1	-0.4	6.8	3.1	45.6	97.8	-1.3	11.8	7.7	65.5	97.3	-1.1
1973	9.8	7.5	5.9	78.9	97.4	-0.5	9.3	12.0	129.3	101.0	0.3	16.7	17.0	107.0	101.0	0.2
1974	9.8	9.5	9.8	94.8	99.1	-0.1	8.8	10.6	122.8	101.7	0.9	18.2	19.4	106.7	101.1	0.3
1975	12.7	6.2	5.2	84.7	99.2	-0.4	5.0	10.6	162.0	102.0	1.0	13.7	15.7	115.1	101.9	0.6
1976	11.3	5.8	4.3	87.1	98.9	-0.2	4.4	5.8	130.8	100.6	0.6	9.8	10.1	112.3	100.8	0.3
1977	14.6	4.5	5.2	114.2	101.2	0.3	3.8	7.8	205.4	102.3	1.9	8.3	12.9	155.0	103.4	1.5
TOTAL	10.5	6.6	5.8	86.8	95.7	-0.9	7.1	8.5	119.7	100.1	1.5	13.7	14.2	104.2	101.5	0.4
PRCNTL	61.2	0.8	10.2	25.9	25.5	29.9	17.8	49.8	81.6	65.7	79.6	0.6	19.0	55.1	56.5	52.4

——— HFPA=421 HFPANAME=HAYWARD COUNTY=ALAMEDA HSANAME=EAST BAY ———

COHORT	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	5	7516	78.2	10.2	9.7	2.0	1.6	11.4	13.8	5.9	5.3	40.7	0.5	1.2	2.3	7.8
1971	5	7379	68.1	18.6	10.4	2.9	1.3	11.4	13.1	5.7	4.5	40.8	0.3	1.2	1.7	7.3
1972	5	6713	65.7	20.8	10.7	2.8	1.3	11.4	12.4	6.4	4.4	42.3	0.4	1.2	2.4	7.4
1973	5	6468	65.1	20.2	11.4	3.3	1.3	12.8	10.6	5.9	4.2	43.3	0.4	1.1	1.6	7.0
1974	5	6829	63.9	20.3	12.3	3.4	4.0	13.9	11.4	6.1	3.0	42.7	0.4	0.9	2.3	7.1
1975	6	6448	62.5	19.7	12.8	4.8	7.7	15.9	11.2	5.0	3.9	44.4	0.5	0.7	2.0	7.3
1976	5	6773	60.2	20.1	13.6	6.1	1.1	17.0	10.9	4.9	4.1	43.8	0.5	0.5	2.1	7.3
1977	5	6962	59.8	20.2	13.1	6.9	0.8	17.8	11.8	5.4	4.2	44.3	0.6	0.5	1.7	6.9
TOTAL	6	54781	64.5	19.7	11.7	4.0	2.4	13.9	11.9	5.8	4.3	42.7	0.4	0.9	2.0	7.3
PRCNTL	.	98	38.1	63.3	88.4	56.5	59.9	78.7	15.6	39.5	39.5	58.3	68.8	25.9	69.4	78.2

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BBFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	6.6	9.8	6.9	78.4	88.0	-2.7	12.2	11.3	92.6	96.2	-0.9	21.2	18.1	85.3	89.8	-2.3
1971	8.8	9.8	8.3	88.8	92.7	-1.8	10.9	10.9	100.5	100.2	0.1	19.2	18.0	98.1	98.7	-0.3
1972	9.8	8.7	7.4	85.4	90.9	-1.2	11.0	10.7	97.0	98.6	-0.3	19.4	18.0	93.0	95.5	-1.0
1973	10.1	8.7	6.7	76.9	88.0	-1.9	10.0	8.1	81.3	92.3	-1.9	17.4	14.7	84.3	90.5	-2.0
1974	13.1	8.6	9.0	105.0	103.1	0.4	8.1	6.8	84.0	94.2	-1.4	16.0	15.0	93.9	96.3	-0.8
1975	14.8	7.7	7.0	100.5	100.3	0.2	7.9	5.8	73.4	91.2	-2.3	15.9	13.5	84.8	91.1	-1.9
1976	15.4	8.2	8.1	99.2	99.5	-0.1	8.1	8.2	100.8	100.3	0.1	15.5	16.2	104.5	102.7	0.8
1977	10.2	7.1	5.7	80.3	88.6	-1.5	6.8	5.8	85.4	95.3	-1.2	13.4	11.5	86.0	92.3	-1.6
TOTAL	11.8	8.5	7.4	87.6	89.3	-2.9	9.4	8.5	90.5	92.1	-2.7	17.4	15.9	91.2	92.3	-3.4
PRCNTL	76.9	60.7	37.4	27.9	10.9	6.1	77.6	40.3	19.7	3.4	3.4	78.7	30.8	17.8	6.8	3.4

TABLE 9. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 5 BY HFPA OF OCCURRENCE
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

HFPA=2001 HFPANAME=FEDERAL HOSPITALS COUNTY=ALAMEDA HSANAME=EAST BAY

COHORT	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTMED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	1	1423	74.6	4.1	10.1	11.1	1.4	3.7	10.4	3.9	5.0	55.0	0.6	1.2	2.0	7.0
1971	1	1392	75.1	5.9	8.7	10.2	3.3	3.5	15.3	3.2	5.1	51.4	0.5	1.6	2.7	6.0
1972	1	1270	70.9	5.0	11.4	12.7	0.6	4.0	16.9	4.0	5.0	52.9	0.5	0.7	1.1	6.6
1973	1	1070	69.6	4.8	11.7	13.9	1.4	4.1	14.9	4.7	5.4	50.4	0.9	1.2	1.0	7.0
1974	1	1220	69.3	4.5	12.5	13.8	1.1	4.6	13.3	4.9	3.3	55.4	0.5	0.2	2.1	7.0
1975	1	1004	65.2	4.1	13.5	17.3	1.5	4.7	14.1	5.0	4.2	49.9	0.4	0.4	2.2	9.1
1976	1	1372	64.7	5.9	12.2	17.2	0.5	5.1	12.0	4.1	4.0	51.2	0.6	0.4	3.0	8.4
1977	1	1266	62.4	6.9	13.1	17.6	0.3	6.0	14.0	5.1	3.3	52.2	0.2	0.2	2.4	8.0
TOTAL	1	10041	69.2	5.2	11.6	14.1	1.3	4.5	15.1	4.4	4.4	52.4	0.5	0.7	2.2	7.7
PRCNTL	.	57	44.2	8.2	87.0	97.3	26.5	9.5	61.2	20.4	40.9	95.9	70.9	16.3	87.1	85.7

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	6.0	9.0	9.1	101.7	100.4	0.1	9.6	12.1	125.0	102.9	1.1	10.9	21.1	111.6	103.0	2.7
1971	5.2	8.2	9.3	113.4	100.3	0.5	10.5	13.1	124.2	103.7	1.2	10.3	22.3	121.5	105.9	1.4
1972	4.7	8.7	3.5	40.1	86.7	-2.0	12.5	16.5	131.0	105.3	1.7	20.2	20.3	101.0	100.3	2.1
1973	7.9	8.9	8.3	93.4	98.6	-0.2	9.1	9.4	102.0	100.3	0.1	10.6	17.6	94.6	98.7	-0.3
1974	11.3	9.4	4.1	42.2	85.6	-2.1	10.0	13.1	121.5	102.0	1.0	10.6	17.1	92.2	98.1	-0.5
1975	11.3	8.6	5.0	57.9	91.6	-1.4	11.6	12.0	102.2	100.4	0.1	10.0	16.9	94.1	98.0	-0.3
1976	12.9	10.5	10.9	104.1	101.3	0.2	9.3	8.0	94.0	99.3	-0.2	21.1	19.7	93.1	97.6	-0.5
1977	15.4	9.0	11.1	112.4	102.4	0.5	10.0	12.0	127.4	103.9	1.3	20.2	23.7	117.6	105.5	1.2
TOTAL	9.2	9.2	7.9	80.0	92.1	-1.5	10.4	12.2	117.6	109.0	2.3	19.3	20.0	103.0	102.4	0.7
PRCNTL	41.5	82.3	44.9	22.4	12.2	16.3	85.0	91.0	70.2	94.6	93.2	86.4	84.4	51.0	63.3	38.5

HFPA=0001 HFPANAME=NONHOSPITAL SITES COUNTY=ALAMEDA HSANAME=EAST BAY

COHORT	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTMED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	0	69	47.1	17.1	27.1	8.6	30.0	24.6	10.2	7.1	11.4	37.1	1.4	4.3	11.4	25.7
1971	0	75	61.7	11.1	24.7	2.5	29.6	44.3	12.5	7.7	10.3	50.6	1.3	6.2	1.2	12.0
1972	0	73	70.1	5.2	23.4	1.3	29.9	40.2	15.9	6.5	8.2	42.9	1.4	2.6	1.3	13.7
1973	0	81	71.4	4.8	19.0	4.8	15.3	30.7	15.6	7.2	4.8	40.4	1.2	0.0	2.4	8.6
1974	0	112	68.1	10.3	18.1	3.4	25.9	37.4	13.2	1.7	4.3	41.4	0.9	1.7	0.9	10.5
1975	0	96	68.0	12.4	15.5	4.1	23.7	37.5	16.1	5.2	3.1	42.3	1.0	4.1	2.1	12.5
1976	0	109	60.2	7.1	22.1	10.6	17.7	31.0	17.2	2.7	3.6	42.9	0.9	2.7	0.0	10.1
1977	0	164	70.3	8.5	15.2	6.1	13.9	24.5	14.4	1.0	6.7	45.5	1.2	1.2	1.2	5.5
TOTAL	0	779	65.5	9.3	19.8	5.4	22.0	30.7	13.3	4.4	6.2	43.0	1.1	2.6	2.1	11.3

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	0.0	37.5	130.4	347.4	110.1	4.5	47.4	88.7	140.7	101.5	1.0	111.4	100.4	169.2	111.1	3.2
1971	0.0	20.2	26.7	131.0	101.5	0.5	17.0	27.4	154.3	100.9	0.0	40.4	53.3	132.1	102.3	0.9
1972	0.0	18.1	41.1	227.5	105.0	1.7	35.0	57.1	159.5	102.9	1.6	43.5	95.9	228.4	100.2	3.4
1973	1.2	0.6	12.3	142.0	100.0	0.4	10.0	12.5	124.4	100.2	0.3	10.0	24.7	137.4	100.7	0.5
1974	0.0	15.2	0.9	30.0	97.6	-0.7	21.4	10.0	84.2	99.0	-0.5	27.3	26.0	97.6	99.0	-0.1
1975	0.0	12.1	10.4	80.1	99.5	-0.2	0.1	10.5	130.6	100.2	0.3	23.3	20.0	80.6	99.7	-0.2
1976	0.0	14.2	0.0	0.0	95.5	-1.4	20.9	9.2	43.9	98.2	-1.2	29.6	9.2	31.0	96.1	-1.0
1977	0.0	7.2	12.2	160.0	102.2	0.0	3.3	0.0	0.0	99.6	-0.7	14.1	12.2	86.6	99.6	-0.2
TOTAL	0.1	15.0	24.4	162.1	109.1	2.4	17.6	19.7	111.9	101.7	0.6	33.6	43.6	129.7	106.3	2.2

HFPA=0007 HFPANAME=NONHOSPITAL SITES COUNTY=CONTRA COSTA HSANAME=EAST BAY

COHORT	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTMED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	0	24	75.0	8.3	4.2	12.5	4.2	4.0	4.3	0.0	12.5	4.2	0.0	8.3	16.7	37.5
1971	0	23	56.5	17.4	21.7	4.3	26.1	34.8	31.6	9.1	0.0	17.4	0.0	0.0	4.3	27.3
1972	0	27	74.1	3.7	22.2	0.0	18.5	40.8	30.8	14.8	3.7	51.9	0.0	0.0	7.4	34.6
1973	0	22	81.8	0.0	18.2	0.0	13.6	28.6	29.4	13.6	9.1	22.7	0.0	0.0	4.5	25.0
1974	0	39	71.8	5.1	12.8	10.3	15.4	28.9	13.6	5.1	5.1	43.6	0.0	2.6	2.6	12.0
1975	0	37	73.0	8.1	13.5	5.4	21.6	36.1	17.4	5.4	0.0	37.8	0.0	0.0	2.7	11.4
1976	0	49	75.5	10.2	6.1	8.2	20.4	14.6	15.8	4.2	2.1	33.3	0.0	2.1	0.0	8.5
1977	0	59	71.2	11.9	11.9	5.1	13.6	11.9	12.5	5.1	3.4	32.2	0.0	0.0	0.0	3.4
TOTAL	0	272	72.5	8.5	12.9	6.1	16.0	23.2	17.5	6.5	4.0	32.3	0.0	1.4	3.6	16.2

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	0.0	52.5	125.0	237.9	100.3	1.0	116.6	142.9	122.5	102.0	0.0	161.0	250.0	134.5	104.0	2.2
1971	0.0	58.9	0.0	0.0	95.4	-1.4	100.1	90.9	84.1	99.1	-0.5	127.3	90.9	71.4	97.4	-0.9
1972	0.0	36.6	76.9	210.3	102.9	1.2	52.4	125.0	210.5	101.7	1.0	87.4	192.3	220.0	103.7	2.2
1973	0.0	27.1	50.0	184.5	101.3	0.7	39.2	52.6	134.1	100.3	0.4	61.3	100.0	164.0	101.1	0.9
1974	0.0	16.1	25.6	150.9	101.1	0.5	10.5	0.0	0.0	99.7	-0.7	29.4	25.6	80.5	99.0	-0.1
1975	0.0	10.7	20.6	285.9	101.7	1.1	10.5	0.0	0.0	99.7	-0.6	26.0	20.6	106.5	100.1	0.1
1976	0.0	5.2	21.3	400.0	101.9	1.5	4.2	0.0	0.0	99.9	-0.4	9.5	21.3	224.4	100.5	0.0
1977	0.0	10.2	0.0	0.0	97.9	-0.9	17.2	16.9	90.7	100.0	-0.0	20.6	16.9	82.3	99.3	-0.4
TOTAL	0.0	21.7	33.1	152.5	104.2	1.4	33.4	30.0	113.7	101.6	0.6	51.1	69.9	136.6	104.9	2.0

TABLE 10. Examples (A & B) of 1970-1977 California vital record data by hospital of birth.

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             TABLE 10. EXAMPLES (A&B) OF 1970-1977 CALIFORNIA VITAL RECORD DATA BY HOSPITAL BIRTH
         SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

------------------------------------------------ NAME:A ------------------------------------------------

COHORT BIRTH WHITE SPAN BLACK OTHER NOPRE OUTMED SHORT TEEN OLDER PARA1 OPARA1 PARA6 MULT LOBW

1970     952 28.7  15.6 46.9    8.8   8.2  32.5  24.8  12.1   5.2 43.8    0.1    4.2  3.1 15.5
1971     858 29.5  16.5 45.1    8.9  14.2  33.2  26.4  12.8   4.3 46.6    0.2    4.8  2.6 15.9
1972     676 27.1  16.4 45.7   10.8  15.7  40.7  22.0  14.1   3.5 46.7    0.0    3.7  1.8 14.8
1973     557 25.4  14.9 52.7    6.9  17.4  42.8  20.2  11.9   5.3 46.2    0.4    2.5  3.2 16.3
1974     506 21.3  17.0 53.6    8.1  15.8  43.8  17.7  13.2   3.9 46.5    0.2    2.2  2.0 14.8
1975     522 19.4  16.4 54.9    9.3  18.3  46.2  22.3  15.3   4.3 40.3    0.2    1.3  4.8 17.4
1976     560 19.7  20.4 52.9    6.9  15.6  40.0  19.8  13.0   6.2 45.6    0.7    2.8  2.5 13.9
1977     536 18.7  18.2 53.4    9.6  19.5  51.2  18.5  10.6   5.3 46.9    0.4    3.3  0.6 12.3
TOTAL   5167 24.6  16.8 49.8    8.8  14.9  40.8  21.0  12.7   4.7 46.0    0.3    3.1  2.6 15.0
PRCNTL    62  0.6  40.3 97.7   88.4  98.6  96.1  90.9  95.8  43.8 81.5   29.7   81.8 93.8 99.5

COHORT CSEC EXFMR OBFMR ISFMR BBFMR ZFMR EXNMR OBNMR ISNMR BBNMR ZNMR EXPMR OBPMR ISPMR BBPMR ZPMR

1970    7.3 18.3  18.9  103.6 101.8  0.2 22.9  20.3   80.7  94.3 -0.7 39.4  38.9   90.6  99.2 -0.1
1971    6.7 20.8  23.3  112.2 106.4  0.6 26.9  29.8  110.9 105.9  0.0 44.1  52.4  119.0 112.3  1.7
1972    8.2 20.4  17.8   86.9  93.8 -0.6 20.0  27.1   96.8  98.3 -0.2 46.1  44.4   96.4  97.7 -0.3
1973    8.9 16.1   3.6   22.3  73.5 -2.6 20.8  25.2  121.5 107.2  1.0 34.3  28.7   83.6  92.9 -1.8
1974   10.3 14.9   4.0   26.3  60.6 -2.2 20.4  17.9   87.4  93.8 -0.6 30.1  21.7   72.2  86.3 -1.5
1975   11.4 15.8  11.5   72.8  87.0 -0.9 18.1  11.6   64.1  84.1 -1.5 29.5  23.8   70.1  89.8 -1.1
1976   10.8 14.6  16.1  118.3 104.6  0.3 16.9  10.9   64.5  83.5 -1.5 29.3  26.8   91.5  95.6 -0.5
1977   10.4 14.0  22.4  159.7 125.7  1.8 11.8   9.5   86.6  95.9 -0.4 27.8  31.7  117.3 108.6  0.9
TOTAL   8.9 17.3  15.7   90.5  93.2 -1.0 21.4  20.1   93.7  95.3 -0.9 36.2  35.4   97.8  98.2 -0.4
PRCNTL 42.9 99.1  94.1   34.9  22.8 23.1 99.1  97.5   34.9  22.0 22.4 99.1  97.3   39.5  34.9 35.4

------------------------------------------------ NAME:B ------------------------------------------------

COHORT BIRTH WHITE SPAN BLACK OTHER NOPRE OUTMED SHORT TEEN OLDER PARA1 OPARA1 PARA6 MULT LOBW CSEC

1970    1046  22.1  29.6 46.9   1.5   1.0  27.7  18.8   8.9   6.1 33.2    0.4    5.4  3.4 10.2  6.4
1971     939  19.8  26.6 51.8   1.9   0.9  30.8  21.3   9.4   5.5 33.7    0.3    4.6  2.8 10.7  7.1
1972     568  11.6  26.4 61.3   0.7   1.4  34.6  18.4  11.1   7.4 34.8    0.2    5.0  2.3 11.8  4.2
1973     559   5.8  17.1 77.5   0.4   2.3  48.3  18.2  12.8   5.7 39.3    0.2    4.1  1.8 10.8  7.7
1974     803   3.5  13.6 81.9   1.1   3.3  54.2  19.2  14.3   3.7 40.7    0.2    2.5  3.5 12.5  8.8
1975    1008   1.8   8.1 89.1   1.0   2.0  67.0  17.7  13.1   4.0 44.2    0.2    1.6  1.4 12.0  9.3
1976    1210   2.3  12.9 83.9   0.9   0.8  62.7  15.7  13.1   3.8 41.0    0.0    2.6  1.6 11.7 12.5
1977    1137   2.0  12.1 83.2   2.7   2.5  64.3  17.2  11.6   4.8 40.7    0.2    1.6  3.8 12.5 14.3
TOTAL   7270   8.3  17.7 72.6   1.4   1.7  50.3  18.2  11.8   4.9 38.6    0.2    3.3  2.5 11.5  9.2
PRCNTL    72   3.4  51.8 99.1  15.4  52.2  98.2  76.9  92.3  58.8 17.8   23.1   83.4 91.8 97.3 44.9

COHORT EXFMR OBFMR ISFMR BBFMR ZFMR EXNMR OBNMR ISNMR BBNMR ZNMR EXPMR OBPMR ISPMR BBPMR  ZPMR

1970    12.1  15.3  120.5 111.2  1.0 12.6  15.5  123.4 107.6  1.1 24.8  30.6  123.3 111.6   1.6
1971    12.5  13.8  111.1 104.4  0.4 13.0  14.8  101.4 100.5  0.1 26.1  27.7  106.1 103.0   0.4
1972    12.5  22.9  102.5 123.4  2.4 12.6  16.2  129.2 105.5  0.9 25.5  30.7  151.6 117.0   2.4
1973    12.6  21.5  170.0 120.0  2.0 15.7  25.6  162.7 116.0  2.5 27.3  46.5  170.5 126.3   3.6
1974    14.6  11.2   76.5  87.3 -0.9 10.4  21.4  116.5 109.7  0.9 30.1  32.4  107.5 104.7   0.5
1975    13.5  19.6  147.3 127.7  2.8 11.8  18.2  154.6 125.8  2.4 26.8  37.7  145.0 120.5   3.2
1976    11.3   7.4   65.6  80.5 -1.4 12.4  17.5  141.4 123.8  2.1 21.6  24.8  114.6 100.7   0.9
1977    12.6  13.2  105.0 102.9  0.2 14.4  21.4  140.3 120.4  2.7 25.4  34.3  134.9 122.5   2.5
TOTAL   12.6  14.7  118.5 111.8  1.7 13.8  18.4  123.8 123.9  4.4 25.5  32.9  120.7 122.6   3.2
PRCNTL  95.9  93.8   72.1  88.9 85.9 95.5  96.6   87.5  99.5 99.5 95.2  96.1   87.8 100.0 100.0
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TABLE 11. Examples (C & D) of 1970-1977 California vital record data by hospital of birth.

TABLE 11. EXAMPLES (C&D) OF 1970-1977 CALIFORNIA VITAL RECORD DATA BY HOSPITAL BIRTH
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

NAME:C

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	231	74.3	21.9	1.7	2.1	0.7	7.6	15.5	7.5	5.1	30.0	0.0	1.4	2.1	8.6
1971	305	64.3	30.2	4.6	1.0	0.3	14.9	17.6	8.5	3.0	44.3	0.0	1.3	2.6	5.6
1972	292	64.5	28.0	6.1	1.4	0.3	9.0	14.0	10.6	4.4	41.6	0.3	0.3	2.0	7.2
1973	346	59.7	33.1	5.2	2.0	1.2	14.3	15.1	12.7	6.1	44.7	0.9	3.2	2.3	6.3
1974	476	46.9	41.9	7.9	3.3	5.4	18.3	23.2	12.9	4.2	45.9	0.4	2.9	1.3	6.7
1975	531	43.3	49.4	5.6	1.7	4.9	19.9	20.3	15.5	4.3	44.0	0.0	3.6	3.0	7.7
1976	572	32.4	57.1	7.5	3.0	7.7	27.6	25.0	15.0	5.1	40.6	0.2	4.4	2.0	7.2
1977	311	36.2	52.8	8.5	2.5	11.2	20.6	20.7	11.4	4.2	41.2	0.4	2.9	1.5	6.3
TOTAL	3324	49.0	42.5	6.3	2.2	4.8	19.3	20.2	12.4	4.5	42.7	0.2	2.8	2.2	6.9
PRCNTL	48	26.3	81.4	68.0	25.5	85.9	76.9	64.0	93.9	40.1	53.3	27.4	77.0	81.0	62.6

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXMMR	OBMMR	ISMMR	BSMMR	ZMMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	4.1	9.1	3.4	37.0	92.1	-1.1	12.1	13.0	113.9	101.5	0.3	19.1	17.2	98.1	98.5	-0.3
1971	5.9	6.1	9.0	162.3	105.3	0.9	6.6	3.3	58.5	97.4	-0.8	12.4	13.1	106.1	100.5	0.1
1972	4.1	6.6	17.1	250.6	114.0	2.3	6.0	7.0	116.0	100.7	0.2	14.0	24.0	171.1	106.9	1.6
1973	4.3	5.7	14.5	254.1	113.5	2.2	5.0	5.9	116.4	100.7	0.2	16.6	28.2	198.1	107.2	1.0
1974	0.8	0.0	0.4	185.2	101.3	0.1	7.7	12.7	166.0	113.0	1.6	14.6	21.0	143.0	111.1	1.4
1975	9.7	7.2	11.3	156.6	114.2	1.2	9.3	17.1	184.9	124.0	2.5	15.1	20.2	186.7	125.5	3.0
1976	10.6	6.5	0.7	134.0	100.3	0.7	5.6	0.0	156.0	110.4	1.2	12.2	17.5	143.9	111.2	1.4
1977	11.4	10.2	17.6	172.9	125.1	1.9	9.9	12.0	121.1	106.4	0.6	20.9	29.4	140.6	117.6	1.9
TOTAL	6.1	7.5	11.4	152.2	120.4	2.0	7.0	10.7	137.1	112.7	2.3	15.0	22.0	146.9	120.9	4.0
PRCNTL	35.6	36.7	82.0	98.7	97.3	98.1	39.7	76.2	80.9	95.7	94.3	32.7	81.2	93.4	99.0	99.1

NAME:D

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW	CSEC
1973	1882	2.3	28.5	68.6	0.6	11.3	49.1	23.1	17.2	5.1	44.2	0.3	4.5	2.7	14.1	8.5
1974	2168	3.2	39.2	57.0	0.6	0.3	45.9	23.3	14.7	5.3	39.0	0.6	4.3	2.7	13.1	8.9
1975	2712	3.7	52.3	43.2	0.8	7.1	41.3	23.5	13.5	5.9	40.8	0.4	5.0	2.7	12.0	11.2
1976	3717	4.6	60.0	33.8	1.6	6.0	40.5	22.3	11.7	5.0	39.6	0.5	4.7	2.3	10.1	11.6
1977	4109	4.8	66.1	27.6	1.5	7.1	39.5	23.5	10.3	5.0	38.4	0.3	4.7	1.7	9.3	12.5
TOTAL	14588	4.0	53.4	41.4	1.2	7.5	42.3	23.1	12.0	5.7	39.0	0.4	4.6	2.3	10.9	11.0
PRCNTL	90	1.6	89.3	96.4	11.0	92.7	96.6	98.1	95.2	71.0	26.1	56.9	93.4	87.5	95.9	66.2

COHORT	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXMMR	OBMMR	ISMMR	BSMMR	ZMMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1973	13.4	10.5	70.6	87.7	-1.1	14.4	20.2	140.6	119.3	2.5	27.3	30.5	111.9	107.5	1.0
1974	13.0	14.3	110.3	107.5	0.6	12.5	14.5	116.4	111.0	1.1	26.2	29.6	109.1	107.0	0.9
1975	15.0	17.3	109.4	107.7	0.7	13.4	16.9	125.7	119.4	2.1	30.3	33.9	112.1	110.4	1.6
1976	11.9	15.6	130.0	125.1	2.3	0.0	12.0	136.2	125.1	2.5	22.1	27.4	124.4	120.2	2.9
1977	11.0	11.2	101.7	101.4	0.1	9.4	17.0	100.0	159.7	6.3	20.9	20.0	134.2	120.7	4.2
TOTAL	12.7	13.9	100.0	107.3	1.3	11.1	15.7	141.0	132.6	6.7	24.5	29.4	119.7	117.3	4.9
PRCNTL	96.1	91.0	62.1	70.2	80.7	87.1	95.5	98.5	100.0	100.0	94.3	97.0	79.0	98.4	99.5

TABLE 12. Examples (E & F) of 1970-1977 California vital record data by hospital of birth.

TABLE 12. EXAMPLES (E&F) OF 1970-1977 CALIFORNIA VITAL RECORD DATA BY HOSPITAL BIRTH
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORN

NAME:E

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTMED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	885	83.7	12.9	0.9	2.5	1.7	7.0	14.7	3.9	4.2	43.1	0.2	0.7	2.3	6.3
1971	1037	81.7	13.3	1.3	3.7	2.9	8.3	13.2	4.7	5.2	41.9	0.3	1.2	1.7	6.3
1972	1364	79.9	13.6	2.0	4.5	2.2	10.1	12.7	4.0	5.0	43.0	0.6	0.9	1.0	5.9
1973	1554	77.7	14.2	2.5	5.5	2.6	12.3	12.1	6.2	5.2	46.4	0.6	0.8	2.1	6.4
1974	1823	72.8	18.3	3.6	5.4	3.1	13.7	10.9	5.6	4.2	45.1	0.7	0.8	2.1	5.6
1975	2384	64.8	23.4	4.5	7.3	4.3	18.0	13.0	6.6	4.7	44.9	0.3	1.1	1.7	7.1
1976	2539	63.1	25.3	4.6	6.9	1.8	19.8	13.2	6.3	5.5	45.5	0.9	0.9	2.1	6.2
1977	2988	57.9	26.0	7.5	8.7	0.9	22.7	12.2	5.2	4.3	46.1	0.6	0.8	1.8	5.1
TOTAL	14534	69.2	20.4	4.1	6.3	2.2	16.0	12.8	5.7	4.8	44.9	0.6	0.9	1.9	6.0
PRCNTL	90	50.1	33.6	39.6	70.5	63.9	66.4	32.2	39.3	48.4	73.0	70.9	24.3	52.8	37.6

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	6.1	8.6	6.8	79.1	93.8	-0.6	10.1	6.8	67.4	91.8	-1.2	18.7	13.6	72.4	89.3	-1.4
1971	9.9	7.9	9.6	121.8	106.8	0.7	9.2	8.8	95.6	98.9	-0.2	16.9	10.3	108.2	123.8	0.4
1972	11.5	8.4	5.9	69.5	87.8	-1.1	9.7	9.6	98.8	99.6	-0.1	19.4	13.4	79.4	89.2	-1.4
1973	10.8	7.6	7.7	101.1	108.4	0.8	7.8	6.5	83.5	95.4	-0.7	15.2	14.2	93.2	97.1	-0.4
1974	12.6	7.2	7.7	106.4	103.5	0.2	7.2	4.4	81.6	81.6	-1.7	13.5	12.1	89.6	94.3	-0.6
1975	15.3	8.1	6.3	78.2	85.8	-1.8	8.2	9.4	113.7	107.8	0.7	15.9	15.7	98.3	98.8	-0.1
1976	20.6	7.8	4.7	67.7	79.9	-1.5	6.7	8.3	123.6	112.8	1.2	13.1	13.8	99.1	99.5	-0.1
1977	21.9	6.3	3.7	58.5	73.7	-1.9	6.5	7.4	112.2	107.7	0.7	12.1	11.0	98.9	94.1	-0.7
TOTAL	15.3	7.4	6.8	81.4	86.2	-2.1	7.8	7.7	98.9	99.2	-0.1	14.8	13.7	92.1	93.8	-1.4
PRCNTL	93.4	33.8	19.3	20.8	7.5	7.3	39.8	36.1	44.9	39.7	42.4	38.8	21.8	28.6	15.2	14.7

NAME:F

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTMED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	288	81.7	15.8	0.7	2.7	1.3	11.1	15.8	7.8	5.8	38.7	0.3	4.7	2.7	9.1
1971	406	76.5	19.4	1.5	2.7	2.8	15.1	12.4	5.4	6.1	41.4	0.2	2.7	2.5	6.9
1972	277	80.5	15.9	0.7	2.9	1.1	9.9	13.6	7.9	5.4	44.4	0.4	1.1	2.2	8.3
1973	346	80.7	12.9	0.9	5.5	3.2	12.8	9.7	9.5	4.9	48.8	0.6	1.4	3.2	5.8
1974	357	81.8	13.7	1.1	3.4	1.7	4.8	9.9	4.5	5.0	40.1	0.6	0.3	1.1	4.2
1975	406	79.3	13.5	1.7	5.4	3.0	6.2	12.8	4.2	4.7	40.1	0.2	0.5	2.5	5.4
1976	438	78.6	14.0	0.7	6.7	2.1	5.9	10.1	3.3	4.7	47.2	1.4	0.5	1.4	8.1
1977	413	75.4	17.9	1.4	5.3	3.6	9.1	11.8	3.4	5.6	49.3	0.5	0.3	2.7	4.8
TOTAL	2932	79.1	15.3	1.1	4.5	2.3	9.2	11.8	5.4	5.2	43.8	0.5	1.4	2.2	6.5
PRCNTL	44	78.5	42.4	32.4	64.6	64.9	33.3	28.9	37.2	57.6	54.9	71.4	47.4	83.2	49.4

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	6.3	14.2	13.4	94.2	98.8	-0.1	11.7	18.2	87.5	98.7	-0.3	25.3	23.5	88.2	94.4	-0.8
1971	7.6	9.3	12.3	132.9	105.8	0.7	8.5	7.5	87.9	98.6	-0.3	28.2	19.7	97.6	99.4	-0.1
1972	9.7	7.9	10.1	229.5	113.2	2.8	18.8	11.8	118.6	101.1	0.2	19.9	28.9	145.8	107.4	1.3
1973	16.7	7.2	14.5	290.8	111.6	1.7	12.4	14.7	118.8	102.9	0.5	19.1	28.9	151.3	109.9	1.7
1974	14.8	6.4	5.6	87.4	97.9	-0.2	5.5	6.5	153.3	105.3	0.8	11.7	14.8	119.8	103.1	0.5
1975	14.8	4.3	9.9	219.3	115.6	1.6	4.3	10.8	230.2	110.2	1.7	9.1	19.7	217.4	114.2	2.3
1976	24.7	9.2	14.0	151.4	114.7	1.1	3.9	7.1	182.3	106.2	1.1	10.8	20.9	116.5	105.5	3.6
1977	24.2	6.7	14.5	217.9	124.8	2.1	6.4	4.9	76.2	95.9	-0.5	13.2	19.4	146.6	118.9	1.4
TOTAL	15.5	8.8	12.6	157.4	122.2	3.3	7.5	9.8	119.5	105.9	1.1	17.1	21.5	125.8	112.3	2.3
PRCNTL	93.9	51.3	88.8	98.1	98.8	96.6	32.4	55.8	77.1	81.8	75.7	61.8	88.7	85.7	94.1	91.8

TABLE 13. Examples (G & H) of 1970-1977 California vital record data by hospital of birth.

TABLE 13. EXAMPLES (G&H) OF 1970-1977 CALIFORNIA VITAL RECORD DATA BY HOSPITAL BIRTH
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORN

NAME:G

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	3216	74.5	11.4	11.5	2.6	1.0	14.5	13.0	4.0	5.7	52.2	1.5	0.4	2.2	7.5
1971	3257	66.4	17.4	11.6	4.6	0.6	10.0	13.1	3.4	6.6	51.4	1.9	0.7	2.4	6.9
1972	3686	61.1	18.0	13.9	7.0	1.3	10.4	12.7	2.1	6.7	49.0	1.0	0.6	1.8	6.4
1973	3972	58.9	18.2	14.0	8.9	0.7	11.2	10.6	2.0	7.3	50.1	2.1	0.6	1.9	6.9
1974	4250	53.6	17.6	19.2	9.6	2.6	13.6	9.2	2.6	6.3	51.7	1.7	0.0	2.5	8.1
1975	3977	51.5	18.4	20.7	9.4	2.0	15.5	9.9	2.0	6.9	52.3	2.1	0.5	2.1	8.1
1976	3761	55.3	13.7	21.4	9.5	0.9	15.0	9.7	2.1	6.4	56.3	2.3	0.3	2.2	7.7
1977	5271	45.0	19.0	26.6	9.4	1.9	14.5	10.0	2.6	7.1	57.6	2.7	0.4	2.0	7.2
TOTAL	31390	57.1	16.9	18.0	7.9	1.4	13.3	11.0	2.7	6.7	52.9	2.0	0.5	2.1	7.3
PRCNTL	100	30.7	49.0	80.9	85.9	44.0	55.1	14.7	0.0	84.0	90.0	98.9	5.9	71.7	69.0

COHORT	CSEC	EXFMR	OBFMR	ISFMR	SSFMR	ZFMR	EXNMR	OBNMR	ISNMR	SSNMR	ZNMR	EXPMR	OBPMR	ISPMR	SSPMR	ZPMR
1970	11.3	10.0	13.7	137.4	124.3	2.3	9.0	6.6	67.5	82.9	-2.2	21.7	20.2	93.1	94.5	-0.8
1971	10.3	8.0	9.5	100.2	105.1	0.5	8.3	7.7	93.3	96.9	-0.4	18.3	17.2	93.9	95.9	-0.6
1972	12.0	7.6	4.3	57.3	74.2	-2.4	8.5	6.5	77.0	88.4	-1.5	15.0	10.9	68.7	79.7	-2.0
1973	11.7	7.9	6.3	79.0	87.2	-1.2	7.4	4.0	64.7	83.5	-2.1	15.0	11.1	70.3	80.3	-2.0
1974	13.1	8.3	7.0	93.4	95.3	-0.4	8.6	5.5	63.4	73.9	-2.7	16.4	13.2	80.4	84.7	-2.0
1975	16.5	8.3	8.3	99.0	99.9	-0.0	8.6	5.1	59.2	71.1	-2.9	16.0	13.3	79.2	83.6	-2.1
1976	15.0	8.7	8.0	101.0	100.7	0.1	7.7	4.3	55.4	69.9	-3.0	16.9	13.0	77.1	82.0	-2.3
1977	16.4	7.7	9.1	117.7	114.0	1.2	6.6	5.2	70.4	85.1	-1.5	14.7	14.2	97.0	97.6	-0.3
TOTAL	13.7	8.3	8.4	100.5	100.4	0.1	8.1	5.6	69.5	74.6	-5.7	16.0	14.0	83.0	84.7	-4.0
PRCNTL	85.5	59.9	51.9	49.9	51.2	50.0	40.1	11.0	0.2	0.2	0.2	50.5	24.0	12.3	2.0	0.7

NAME:H

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	1784	61.5	13.3	12.4	12.8	0.4	16.0	14.5	5.1	3.5	57.0	0.4	0.7	2.5	7.9
1971	1634	59.8	13.8	12.6	13.8	1.1	12.3	13.1	3.5	5.0	57.4	1.1	0.5	2.4	5.5
1972	1421	57.4	13.1	13.8	15.7	1.3	13.3	13.2	4.5	4.4	54.1	1.7	0.0	2.0	7.4
1973	1276	56.7	12.8	13.8	16.7	1.3	10.1	13.0	2.6	5.6	54.9	1.0	0.9	0.9	7.9
1974	1452	56.8	13.6	12.5	17.2	2.0	12.9	11.4	2.2	5.2	52.2	1.3	0.2	3.7	10.3
1975	1649	55.6	12.2	13.3	18.9	1.2	10.0	11.9	2.0	5.4	53.7	1.9	0.1	2.6	9.4
1976	1990	57.3	11.4	12.3	19.0	1.3	10.2	13.1	2.4	5.5	58.9	1.4	0.4	2.3	9.7
1977	1826	54.0	12.5	14.0	19.5	1.2	11.1	14.6	2.7	7.2	58.9	1.7	0.2	2.7	10.1
TOTAL	13032	57.4	12.8	13.1	16.7	1.3	12.1	13.2	3.2	5.3	53.9	1.4	0.5	2.5	8.6
PRCNTL	85	37.2	33.8	85.3	96.6	39.5	49.9	37.4	11.1	68.5	98.4	95.9	4.1	95.5	84.1

COHORT	CSEC	EXFMR	OBFMR	ISFMR	SSFMR	ZFMR	EXNMR	OBNMR	ISNMR	SSNMR	ZNMR	EXPMR	OBPMR	ISPMR	SSPMR	ZPMR
1970	8.4	7.7	9.0	115.7	106.6	0.6	7.3	4.0	54.5	87.7	-1.0	16.2	12.9	79.6	98.6	-1.3
1971	9.5	7.9	5.5	69.4	87.1	-1.2	7.0	6.2	79.3	94.3	-0.6	17.0	11.6	60.3	84.4	-2.1
1972	9.6	8.1	7.3	87.4	95.2	-0.5	10.3	5.0	48.2	82.6	-2.4	10.5	12.0	64.6	83.5	-2.2
1973	12.0	8.9	9.4	105.1	102.0	0.2	8.9	9.5	107.0	101.0	0.3	10.1	10.0	103.9	101.7	0.2
1974	15.6	13.4	9.6	72.2	81.7	-1.4	13.6	9.7	71.4	63.0	-1.6	26.2	19.3	73.6	81.6	-2.1
1975	15.6	10.9	9.1	83.2	89.3	-0.0	11.0	4.9	41.5	65.3	-3.2	22.4	13.9	62.2	74.1	-3.0
1976	17.0	10.0	7.5	75.1	83.6	-1.2	10.0	7.1	71.1	82.9	-1.6	19.2	14.6	75.0	83.6	-1.9
1977	20.5	10.3	6.3	50.4	73.4	-2.0	11.5	9.9	86.5	92.1	-0.7	21.6	15.9	75.6	83.5	-1.9
TOTAL	13.9	9.7	7.3	81.0	85.3	-2.3	10.1	7.0	68.9	77.5	-4.3	19.0	14.7	74.5	79.1	-5.1
PRCNTL	87.1	82.5	44.7	19.7	6.3	4.0	79.3	25.2	7.7	3.5	0.7	81.9	29.9	5.4	0.5	0.5

TABLE 14. 1970-1977 California vital record data by size of delivery service.

TABLE 14. 1970-1977 CALIFORNIA VITAL RECORD DATA BY SIZE OF DELIVERY SERVICE
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

DELV	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LODW
ALL_SIZES	503	2623915	50.4	26.3	10.0	5.3	2.90	15.0	14.0	6.1	5.3	43.4	0.61	1.77	1.95	7.0
1-5 BIRTHS	39	102	59.1	24.2	7.1	9.6	23.74	10.4	16.1	7.6	7.6	43.1	2.03	2.54	0.51	29.5
6-250 BIRTHS	142	93779	66.6	24.6	5.0	3.0	3.23	14.7	16.4	0.4	5.0	41.7	0.26	2.34	1.70	6.0
251-500 BIRTHS	94	240099	60.0	27.3	7.0	5.7	2.20	15.4	15.4	7.7	5.0	43.4	0.40	2.02	1.00	6.6
501-1000 BIRTHS	100	569736	62.0	24.1	0.0	4.3	2.69	15.3	14.3	6.3	5.1	43.0	0.51	1.70	1.95	7.0
1001-1500 BIRTHS	62	544339	59.9	27.1	0.1	4.9	2.15	14.0	14.6	5.9	5.3	43.0	0.60	1.59	1.93	6.7
1501-2000 BIRTHS	23	317221	54.7	24.1	13.0	7.3	1.06	16.1	14.1	5.7	5.4	44.1	0.76	1.40	1.99	7.2
>2000 BIRTHS	35	815076	54.0	20.3	12.0	5.7	3.57	14.0	15.0	5.5	5.5	43.4	0.71	1.90	2.01	7.1
NON-HOSPITAL	0	23691	65.3	24.1	7.3	3.2	19.00	10.0	10.0	3.5	5.9	36.2	0.47	3.33	1.57	0.9
UNKNOWN SIZE	0	10992	61.1	22.0	13.1	3.7	3.95	14.4	14.5	6.3	5.7	41.7	0.60	1.04	1.93	0.9

DELV	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
ALL_SIZES	10.0	0.7	0.7	100.0	100.0	0.00	9.0	9.0	100.0	100.0	0.00	17.6	17.6	100.0	100.0	0.00
1-5 BIRTHS	7.6	59.5	131.9	221.5	109.5	4.03	32.7	30.0	116.2	100.4	0.49	135.7	164.0	121.5	104.3	2.03
6-250 BIRTHS	7.7	0.3	9.9	119.4	116.1	5.03	0.3	9.1	110.2	107.0	3.30	16.0	10.9	112.5	110.9	6.09
251-500 BIRTHS	10.0	0.0	0.6	106.9	106.4	3.20	0.0	0.6	106.0	106.0	3.55	16.1	17.1	106.0	105.6	4.53
501-1000 BIRTHS	10.0	0.6	0.5	99.2	99.3	-0.50	9.0	9.0	99.9	99.9	-0.13	17.4	17.4	100.4	100.3	0.44
1001-1500 BIRTHS	10.6	0.4	0.2	97.4	97.5	-1.09	0.7	0.7	99.5	99.6	-0.39	17.0	16.0	99.0	99.0	-1.20
1501-2000 BIRTHS	12.0	0.7	0.5	97.5	97.6	-1.44	9.1	0.7	96.1	96.4	-2.54	17.7	17.1	96.6	96.7	-3.10
>2000 BIRTHS	11.5	9.1	0.6	95.5	95.6	-4.20	9.4	9.2	90.7	90.7	-1.41	10.3	17.0	97.5	97.5	-3.07
NON-HOSPITAL	0.1	12.3	17.3	140.2	126.7	7.70	12.4	14.1	113.7	100.2	3.05	25.7	31.2	121.2	116.2	7.21
UNKNOWN SIZE	9.3	12.2	19.4	150.9	136.2	10.13	9.6	10.1	106.0	102.7	0.97	25.3	29.4	116.2	111.7	4.09

TABLE 15. 1970-1977 California vital record data by type of hospital ownership.

TABLE 15. 1970-1977 CALIFORNIA VITAL RECORD DATA BY TYPE OF HOSPITAL OWNERSHIP
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

OWNER	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
ALL_OWNERSHIPS	503	2623915	50.4	26.3	10.0	5.3	2.90	15.0	14.0	6.1	5.3	43.4	0.61	1.77	1.95	7.0
PRIVATE NONPROFIT	179	1263202	62.0	21.9	9.7	5.6	1.76	14.6	13.3	5.7	5.4	44.5	0.72	1.32	1.95	6.0
PRIVATE PROPRIETARY	111	355975	54.3	31.6	11.0	3.1	1.74	19.5	15.5	7.2	5.1	41.3	0.42	1.99	1.96	6.9
COUNTY/CITY	40	205316	20.4	54.7	13.2	3.6	9.31	26.0	22.4	10.1	5.0	40.4	0.37	4.30	2.02	0.0
KAISER FOUNDATION	15	264172	60.0	19.4	12.7	7.0	2.03	6.5	11.5	3.3	5.4	41.0	0.77	0.96	1.93	5.0
DISTRICT	61	216542	71.5	20.0	3.4	4.3	1.46	10.7	13.1	5.9	5.2	42.7	0.50	1.53	1.00	6.3
FEDERAL	21	115013	72.4	6.4	9.0	11.5	1.17	3.4	15.4	4.3	3.6	51.0	0.36	0.69	1.05	6.3
STATE	5	71705	44.7	40.9	7.9	6.5	7.24	17.5	20.4	6.5	5.4	44.7	0.67	3.07	2.19	9.0
UNKNOWN_OWNERSHIP	63	20219	62.0	21.0	11.0	4.4	4.50	13.0	14.9	6.5	5.6	42.0	0.57	1.94	1.95	0.2
NON_HOSPITAL	0	23691	65.3	24.1	7.3	3.2	19.00	10.0	10.6	3.5	5.9	36.2	0.47	3.33	1.57	0.9

OWNER	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
ALL_OWNERSHIPS	10.0	0.7	0.7	100.0	100.0	0.00	9.0	9.0	100.0	100.0	0.00	17.6	17.6	100.0	100.0	0.00
PRIVATE NONPROFIT	11.0	0.3	7.9	94.9	94.9	-5.72	0.0	0.5	96.2	96.3	-4.00	16.9	16.3	96.3	96.4	-6.67
PRIVATE PROPRIETARY	10.5	0.4	9.0	107.0	107.4	4.62	0.3	0.6	103.0	103.6	2.51	16.7	17.5	105.2	105.0	4.96
COUNTY/CITY	9.0	11.4	12.1	106.0	105.0	3.77	11.2	11.9	106.6	106.2	4.60	22.6	23.0	105.5	105.3	5.60
KAISER FOUNDATION	9.9	7.7	7.9	102.7	102.5	1.30	7.9	0.1	101.5	101.3	0.02	15.5	15.9	102.1	102.0	1.65
DISTRICT	9.9	7.0	7.5	96.7	97.0	-1.46	0.2	0.5	103.7	103.3	1.00	15.0	16.0	100.7	100.7	0.53
FEDERAL	9.3	0.1	7.3	90.1	91.5	-3.30	0.9	9.0	101.2	100.9	0.45	16.9	16.2	95.9	96.3	-2.30
STATE	12.0	11.0	10.9	92.1	93.3	-2.55	12.3	11.7	94.6	95.6	-2.06	24.0	22.4	93.4	94.1	-3.59
UNKNOWN_OWNERSHIP	9.3	11.2	16.5	140.3	132.0	9.50	9.3	10.0	107.4	104.0	1.46	23.1	26.4	114.4	111.1	4.96
NON_HOSPITAL	0.1	12.3	17.3	140.2	126.7	7.70	12.4	14.1	113.7	100.2	3.05	25.7	31.2	121.2	116.2	7.21

TABLE 16. 1970-1977 California vital record data by hospital peer group.

TABLE 16. 1970-1977 CALIFORNIA VITAL RECORD DATA BY CHFC HOSPITAL PEER TYPE
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

CHFCTYPE	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTMED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
ALL_CHFCTYPES	503	2623915	50.4	26.3	10.0	5.3	2.90	15.0	14.0	6.1	5.3	43.4	0.61	1.77	1.95	7.0
LARGE COMPLEX-URBAN	84	1090274	61.7	20.0	12.1	6.3	1.99	13.2	13.2	5.0	5.4	44.1	0.74	1.29	1.97	6.0
AVE. SIZE & COMPLEXITY-URBAN	109	670340	60.3	25.9	9.1	4.0	2.01	15.6	14.1	6.5	4.9	43.3	0.40	1.52	1.92	6.9
LARGE TEACHING-URBAN	13	275373	33.0	40.5	13.4	5.0	0.00	22.0	20.7	7.4	6.1	43.1	0.76	3.54	2.13	0.0
SMALL - RURAL	147	101042	67.4	25.6	2.9	4.1	2.02	11.2	15.0	7.3	4.0	42.3	0.27	2.29	1.03	6.2
SMALL SIZE & COMPLEXITY-URBAN	56	144353	49.2	37.9	0.4	4.5	1.91	16.9	17.0	6.9	5.4	41.8	0.40	2.31	1.03	6.5
UNKNOWN CHFCTYPE	75	114625	66.5	20.0	7.3	6.2	2.17	15.5	14.3	6.9	5.4	44.7	0.67	1.44	1.99	7.1
LARGE - RURAL	19	107409	64.0	29.5	2.0	2.9	2.91	12.2	14.7	7.0	4.0	42.5	0.30	2.20	1.91	6.2
NON-HOSPITAL	0	23691	65.3	24.1	7.3	3.2	19.00	10.0	10.0	3.5	5.9	36.2	0.47	3.33	1.57	0.9

CHFCTYPE	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
ALL_CHFCTYPES	10.0	0.7	0.7	100.0	100.0	0.00	9.0	9.0	100.0	100.0	0.00	17.6	17.6	100.0	100.0	0.00
LARGE COMPLEX-URBAN	11.7	0.5	0.0	94.7	94.0	-5.50	9.0	0.0	90.0	90.0	-2.47	17.2	16.0	97.1	97.2	-4.91
AVE. SIZE & COMPLEXITY-URBAN	11.0	0.4	0.4	99.9	99.9	-0.11	0.7	0.7	100.7	100.7	0.66	17.0	17.1	100.4	100.4	0.50
LARGE TEACHING-URBAN	11.0	11.4	11.2	90.9	90.9	-0.69	11.3	11.1	90.1	90.2	-1.32	22.6	22.2	97.9	97.9	-2.10
SMALL - RURAL	0.0	7.6	0.2	109.0	100.1	3.59	7.6	0.7	114.1	112.0	6.20	15.2	16.0	110.9	110.0	6.09
SMALL SIZE & COMPLEXITY-URBAN	9.0	0.0	0.0	109.0	100.6	3.60	7.7	0.0	103.5	102.9	1.39	15.0	16.0	105.0	105.2	3.35
UNKNOWN CHFCTYPE	0.6	9.1	10.3	113.6	111.0	4.77	9.2	0.0	95.2	96.1	-1.00	10.9	19.0	100.0	100.7	0.40
LARGE - RURAL	9.0	7.0	0.2	104.4	103.7	1.30	0.0	0.1	101.6	101.3	0.56	15.6	16.2	103.7	103.2	1.04
NON-HOSPITAL	0.1	12.3	17.3	140.2	126.7	7.70	12.4	14.1	113.7	100.2	3.05	25.7	31.2	121.2	116.2	7.21

IX. APPENDIX

TABLE 6. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 13 BY OCCURRENCE 13
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

HSA:13 HSANAME:ORANGE COUNTY

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOSW
1970	23887	80.7	15.7	1.2	2.3	1.6	8.4	14.5	3.8	5.9	41.8	0.5	2.1	2.1	7.0
1971	20904	78.0	17.2	1.4	2.5	1.8	7.8	14.9	4.7	5.8	41.4	0.5	2.8	1.9	6.6
1972	20194	76.8	18.8	1.5	2.9	1.7	8.1	14.2	5.3	5.1	42.3	0.4	1.7	2.2	6.6
1973	20166	75.1	20.2	1.6	3.0	2.2	8.2	13.4	5.1	4.9	43.4	0.4	1.6	2.0	6.6
1974	22891	72.6	21.9	2.1	3.4	2.4	9.1	13.6	4.8	4.8	43.8	0.5	1.6	2.0	6.2
1975	21781	69.9	24.8	2.3	3.8	3.1	10.6	13.3	5.1	4.6	43.5	0.5	1.6	2.0	5.9
1976	22840	68.5	25.1	2.1	4.3	3.3	11.7	13.4	4.3	5.0	43.5	0.6	1.5	1.9	6.1
1977	24255	67.3	25.6	2.2	4.9	4.0	12.1	13.4	4.0	4.9	44.2	0.6	1.3	1.8	5.5
TOTAL	179376	73.6	21.1	1.8	3.4	2.5	9.5	13.9	4.8	5.1	43.8	0.5	1.7	2.0	6.3
RANK	11	12.0	6.0	2.0	4.0	5.0	1.0	7.0	2.0	10.0	6.0	10.0	8.0	9.0	3.0

COHORT	CSEC	CXFMR	OBFMR	ISFMR	BBFMR	ZFMR	CXNMR	OBNMR	ISNMR	BBNMR	ZNMR	CXPMR	OBPMR	ISPMR	BBPMR	ZPMR
1970	6.5	9.2	9.1	97.7	98.7	-0.4	10.6	10.7	101.0	100.6	0.2	19.8	19.6	99.1	99.4	-0.2
1971	7.8	8.8	8.1	92.9	96.1	-1.0	10.3	10.3	100.4	100.3	0.1	18.9	18.4	97.4	98.2	-0.7
1972	9.7	8.6	9.0	104.5	102.4	0.6	9.5	9.5	100.4	100.2	0.1	18.4	18.4	99.9	100.0	-0.0
1973	11.2	8.7	8.6	99.6	99.8	-0.1	9.4	9.1	96.7	98.0	-0.6	17.9	17.6	98.4	99.0	-0.4
1974	13.2	8.6	8.8	102.3	101.3	0.3	8.1	9.1	112.3	107.1	2.0	16.6	17.0	107.7	105.0	1.0
1975	14.8	6.8	6.8	100.7	100.4	0.1	6.8	7.1	104.5	102.3	0.6	13.4	13.9	103.1	101.0	0.6
1976	16.3	7.6	7.6	99.0	99.9	-0.0	7.1	7.2	100.6	101.9	0.6	14.6	14.0	101.6	101.0	0.4
1977	17.5	6.8	6.5	98.4	97.6	-0.6	6.2	5.6	90.0	94.0	-1.5	12.8	12.0	93.7	96.2	-1.3
TOTAL	12.3	8.1	8.0	99.1	99.2	-0.4	8.4	8.5	101.2	101.0	0.5	16.5	16.5	100.1	100.1	0.1
RANK	15.0	3.2	6.0	9.0	9.0	9.0	5.0	5.0	8.0	8.0	8.0	4.0	5.0	9.0	9.0	9.0

TABLE 7. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 13 BY COUNTY OF OCCURRENCE 24
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

———— CNTY=30 COUNTY=ORANGE HSA=13 HSANAME=ORANGE COUNTY ————

COHORT	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	19	23057	80.7	15.7	1.3	2.3	1.6	6.4	14.3	5.8	5.9	41.8	0.5	2.1	2.1	7.2
1971	19	20904	78.6	17.2	1.4	2.8	1.8	7.8	14.9	4.7	5.8	41.4	0.5	2.8	1.9	6.6
1972	19	20194	78.8	16.8	1.5	2.9	1.7	8.1	14.2	5.3	5.1	42.5	0.4	1.7	2.3	6.6
1973	21	20166	75.1	20.2	1.6	3.0	2.2	8.2	13.4	5.1	4.9	43.4	0.4	1.6	2.8	6.6
1974	23	22801	72.6	21.9	2.1	3.4	2.4	9.1	13.6	4.8	4.8	43.8	0.5	1.6	2.3	6.2
1975	22	21701	69.9	24.8	2.3	3.0	3.1	10.6	13.3	5.1	4.6	43.9	0.5	1.6	2.8	5.9
1976	24	22840	68.3	25.1	2.1	4.3	3.3	11.7	13.4	4.3	5.8	43.5	0.6	1.5	1.9	6.1
1977	24	24253	67.3	25.6	2.2	4.9	4.0	12.1	13.4	4.8	4.9	44.2	0.6	1.3	1.8	5.5
TOTAL	26	175376	73.6	21.1	1.8	3.4	2.5	9.5	13.9	4.8	5.1	43.0	0.5	1.7	2.0	6.3
PRCNTL	.	95	47.3	64.4	47.3	49.2	39.0	25.4	44.1	11.9	74.6	49.2	81.4	67.8	57.6	49.2

COHORT	CSEC	CXFMR	OXFMR	ISFMR	BSFMR	ZFMR	CXNMR	OXNMR	ISNMR	BSNMR	ZNMR	CXPMR	OXPMR	ISPMR	BSPMR	ZPMR
1970	6.9	9.3	9.1	97.7	98.2	-0.4	10.6	10.7	101.0	100.5	0.2	19.8	19.6	99.1	99.3	-0.2
1971	7.8	8.8	8.1	92.9	94.5	-1.8	10.3	10.3	100.4	100.2	0.1	18.9	18.4	97.4	98.3	-0.7
1972	9.7	8.6	9.0	104.5	102.4	0.6	9.3	9.3	100.4	100.2	0.1	18.4	18.4	99.9	100.0	-0.0
1973	11.2	8.7	8.6	99.6	99.7	-0.1	9.4	9.1	96.7	98.4	-0.6	17.5	17.6	98.4	98.8	-0.4
1974	13.2	8.6	8.0	102.3	101.0	0.3	8.1	9.1	112.3	105.7	2.0	16.6	17.0	107.7	105.0	1.8
1975	14.8	6.8	6.8	100.7	100.3	0.1	6.8	7.1	104.3	101.8	0.6	13.4	13.9	103.1	102.2	0.6
1976	16.3	7.6	7.6	99.8	99.9	-0.0	7.1	7.3	103.6	101.6	0.6	14.6	14.8	101.6	101.1	0.4
1977	17.3	6.0	6.3	95.4	96.3	-0.6	6.2	5.6	90.0	95.9	-1.3	12.0	12.3	93.7	95.5	-1.3
TOTAL	12.3	8.1	8.0	99.1	99.1	-0.4	8.4	8.3	101.2	101.0	0.3	16.5	16.5	100.1	100.1	0.1
PRCNTL	91.3	61.3	47.3	32.2	28.0	28.0	54.2	57.6	32.3	37.6	35.9	57.6	42.4	39.0	39.2	39.3

TABLE 6. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 13 BY COUNTY OF RESIDENCE 24
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

RES=30 COUNTY=ORANGE HSA=13 HSANAME=ORANGE COUNTY

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	26721	81.5	15.8	1.2	2.4	1.5	6.8	14.2	4.9	5.9	40.7	0.5	2.0	2.2	6.7
1971	24359	79.6	16.5	1.3	2.6	1.6	6.6	14.8	4.5	5.7	41.1	0.5	1.9	1.9	6.2
1972	23364	77.9	17.9	1.4	2.8	1.6	7.7	13.9	5.2	5.2	42.2	0.4	1.5	1.9	6.4
1973	23356	76.8	19.4	1.5	3.1	2.0	7.9	12.9	4.9	4.8	43.3	0.4	1.5	1.8	6.3
1974	25018	73.2	21.4	1.9	3.6	2.3	8.6	13.2	4.7	4.8	43.6	0.5	1.5	2.0	5.9
1975	24671	70.9	23.0	2.1	3.9	2.0	9.9	12.2	4.9	4.8	43.8	0.5	1.5	2.0	5.7
1976	25613	69.8	23.9	1.9	4.4	2.9	10.5	13.8	4.2	5.2	43.9	0.6	1.4	1.9	5.9
1977	26625	68.8	24.2	2.0	5.0	3.7	11.1	12.9	4.8	4.9	44.9	0.6	1.3	1.9	5.7
TOTAL	200127	74.7	20.2	1.7	3.5	2.3	8.8	13.5	4.6	5.2	42.9	0.5	1.6	1.9	6.1
PRCNTL	98	50.0	65.5	46.6	46.6	29.3	24.1	43.1	18.3	79.3	41.4	81.0	62.0	51.7	31.0

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	7.2	9.3	9.2	97.8	97.6	-0.5	10.7	10.8	100.5	100.3	0.1	19.7	19.6	99.6	99.7	-0.1
1971	7.9	8.8	8.3	93.7	94.9	-1.0	10.3	10.1	98.7	99.3	-0.2	18.9	18.3	96.9	97.5	-0.8
1972	9.6	8.5	8.7	101.8	101.4	0.2	9.3	9.3	100.7	100.4	0.1	18.8	17.9	99.3	99.4	-0.2
1973	10.9	8.4	8.6	102.3	101.8	0.3	9.1	8.9	98.3	99.1	-0.3	17.2	17.4	101.3	101.0	0.3
1974	13.1	8.4	8.7	103.6	102.9	0.6	7.8	8.6	109.6	104.6	1.6	16.8	17.2	107.1	105.5	1.0
1975	14.6	6.7	6.9	102.1	101.6	0.3	6.7	6.9	102.9	101.2	0.4	13.4	13.7	102.8	102.0	0.6
1976	15.9	7.4	7.5	101.5	101.2	0.2	6.7	7.1	105.2	102.3	0.8	14.1	14.6	103.1	102.3	0.7
1977	17.4	6.9	6.6	98.1	98.2	-0.7	6.3	5.8	98.5	96.7	-1.2	13.1	12.4	94.6	96.8	-1.2
TOTAL	12.1	8.8	8.8	99.3	99.5	-0.2	8.3	8.4	101.8	100.9	0.5	16.3	16.4	100.5	100.5	0.4
PRCNTL	93.1	43.1	40.3	51.7	40.3	58.8	36.2	44.8	51.7	50.6	68.3	39.7	41.4	51.7	56.9	58.6

PAGE INADVERTENTLY OMITTED; WILL BE DISTRIBUTED AT WORKSHOP.

TABLE 9. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 13 BY HFPA OF OCCURRENCE 68
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

HFPA:1014 HFPANAME:HUNTINGTON BEACH COUNTY:ORANGE HSANAME:ORANGE COUNTY

COHORT	HHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	2	2070	88.8	8.1	0.1	3.0	1.2	6.7	12.1	6.3	5.3	37.9	0.4	1.4	2.3	7.4
1971	2	1775	87.5	9.2	0.2	3.0	3.2	6.9	12.4	5.4	5.7	38.0	0.4	1.5	1.2	7.2
1972	2	1713	86.2	9.8	0.3	3.7	2.2	7.4	11.9	5.8	4.7	40.0	0.4	0.9	2.0	6.1
1973	2	1876	82.1	13.6	0.5	3.8	6.1	8.3	10.3	5.1	5.3	38.6	0.2	1.1	2.4	6.0
1974	3	2359	82.3	12.5	1.4	3.8	2.9	9.8	12.1	4.9	5.3	40.7	0.4	1.3	1.1	6.0
1975	3	3326	74.2	18.1	3.4	4.2	5.3	12.3	11.5	5.1	4.5	41.9	0.4	1.0	2.1	6.2
1976	3	3181	75.0	16.1	3.7	5.3	3.1	14.9	11.5	4.6	4.8	42.0	0.4	1.2	2.6	6.0
1977	3	3438	72.6	17.7	3.6	6.2	5.1	14.9	13.0	4.8	4.3	42.6	0.3	0.6	1.9	6.1
TOTAL	3	19738	79.3	14.0	2.1	4.4	3.8	11.8	11.9	5.0	4.8	40.7	0.4	1.1	2.0	6.4
PRCNTL	.	73	63.9	40.0	42.5	58.5	63.0	49.7	17.8	27.2	53.7	22.8	56.5	38.1	60.7	30.3

COHORT	CSEC	EXFMR	OBFMR	ISFMR	SBFMR	ZFMR	EXNMR	OBNMR	ISNMR	SBNMR	ZNMR	EXPMR	OBPMR	ISPMR	SBPMR	ZPMR
1970	7.6	6.7	7.2	63.0	94.3	-0.8	11.4	10.2	89.3	97.7	-0.7	19.2	17.4	90.5	96.5	-0.8
1971	7.5	6.5	6.8	79.7	93.9	-0.6	9.9	9.1	91.9	98.0	-0.4	18.4	15.0	85.9	95.6	-1.0
1972	9.6	6.4	5.8	80.7	97.4	-0.4	7.7	5.9	76.3	97.4	-1.0	13.6	11.7	85.6	96.9	-0.8
1973	10.9	7.3	6.9	95.1	98.7	-0.2	6.8	5.4	67.5	95.5	-1.5	14.6	12.3	82.0	98.5	-1.1
1974	12.3	7.3	5.9	80.9	93.0	-0.8	6.6	6.4	96.2	99.5	-0.2	13.8	12.3	89.0	96.9	-0.7
1975	14.6	6.5	6.6	101.1	100.4	0.1	6.9	6.1	87.4	97.7	-0.7	13.2	12.6	95.9	98.5	-0.3
1976	16.1	7.0	4.1	52.3	88.3	-2.6	9.1	10.7	117.4	104.6	1.2	16.0	14.0	92.1	96.6	-0.7
1977	17.0	7.6	7.3	96.2	98.4	-0.2	6.4	6.2	98.9	98.2	-0.3	14.5	13.4	92.6	96.9	-0.7
TOTAL	13.0	7.5	6.3	62.6	89.3	-2.1	8.1	7.5	92.2	95.3	-1.2	15.2	12.7	90.2	93.2	-2.1
PRCNTL	87.0	34.7	15.8	10.4	10.2	11.6	48.9	22.4	23.0	10.2	14.3	35.4	12.9	15.6	0.0	9.5

HFPA:1015 HFPANAME:SANTA ANA COUNTY:ORANGE HSANAME:ORANGE COUNTY

COHORT	HHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	4	8484	70.0	24.7	2.7	2.6	2.7	9.6	17.6	5.7	6.2	40.0	0.4	3.1	2.0	7.1
1971	4	7668	66.1	28.2	2.9	2.8	2.7	9.1	18.4	5.9	6.1	40.9	0.4	2.9	1.9	6.6
1972	4	7186	62.9	30.9	2.9	3.3	2.6	10.0	18.1	6.5	5.2	41.1	0.3	2.6	2.2	7.1
1973	4	6723	60.4	33.8	2.7	3.1	3.2	10.4	17.4	6.5	5.3	42.4	0.4	2.8	1.7	6.9
1974	5	7518	55.0	38.6	3.1	3.4	4.8	11.8	16.7	6.1	5.4	42.9	0.3	2.9	1.8	6.1
1975	5	6629	51.1	41.9	3.2	3.8	5.0	14.3	17.4	6.3	5.5	42.7	0.5	3.1	1.8	6.3
1976	5	7761	49.6	42.5	2.7	4.1	5.8	14.3	16.7	5.5	5.9	42.3	0.6	2.6	1.5	6.5
1977	6	8895	50.6	41.6	3.0	4.9	7.1	14.8	16.7	5.0	5.0	43.6	0.5	2.5	1.9	6.4
TOTAL	6	60778	58.3	35.2	2.9	3.5	4.2	11.8	17.4	5.9	5.6	42.1	0.5	2.8	1.8	6.6
PRCNTL	.	93	28.5	68.8	51.0	49.7	87.1	56.5	87.8	42.2	76.2	40.8	69.4	85.0	44.2	59.9

COHORT	CSEC	EXFMR	OBFMR	ISFMR	SBFMR	ZFMR	EXNMR	OBNMR	ISNMR	SBNMR	ZNMR	EXPMR	OBPMR	ISPMR	SBPMR	ZPMR
1970	6.6	9.6	9.9	103.4	102.4	0.3	9.9	9.5	95.0	98.1	-0.4	19.0	19.3	97.1	98.8	-0.3
1971	7.3	9.5	9.3	97.7	98.4	-0.2	10.3	10.3	98.1	99.1	-0.2	20.1	19.5	96.6	97.7	-0.3
1972	9.2	9.1	8.3	91.9	94.7	-0.7	11.3	10.4	100.6	100.3	0.1	19.0	18.6	98.3	98.9	-0.2
1973	10.7	9.3	7.9	87.4	92.8	-1.1	9.6	9.3	96.7	98.6	-0.3	18.1	17.1	94.6	96.6	-0.8
1974	12.4	9.2	10.6	115.2	110.2	1.4	8.5	8.2	96.1	98.4	-0.4	17.4	18.8	107.0	105.1	1.1
1975	15.0	8.0	7.7	95.7	97.4	-0.3	6.7	7.4	110.6	103.3	0.8	14.8	15.1	102.2	101.3	0.2
1976	16.7	8.9	7.7	86.9	91.2	-1.2	8.0	6.4	79.8	92.1	-1.9	16.4	14.0	84.5	89.9	-2.2
1977	17.1	7.7	6.7	87.9	92.8	-1.1	7.4	6.8	92.2	96.9	-0.8	14.5	13.3	93.0	95.6	-1.0
TOTAL	12.1	8.9	8.5	96.1	96.6	-1.0	8.9	8.5	95.9	96.6	-1.2	17.5	16.9	96.7	97.8	-1.4
PRCNTL	82.3	77.0	61.9	40.8	31.3	26.5	68.8	46.9	30.6	16.3	15.8	73.5	53.1	30.6	19.7	15.6

HFPA:1016 HFPANAME:NEWPORT BEACH COUNTY:ORANGE HSANAME:ORANGE COUNTY

COHORT	HHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	2	2298	92.3	5.8	0.2	1.8	0.5	6.2	11.6	2.7	5.4	40.6	0.6	0.5	2.8	6.4
1971	2	2249	90.9	6.6	0.2	2.3	0.2	4.1	11.0	2.5	5.3	43.1	0.9	0.6	2.0	6.6
1972	1	2149	90.5	6.5	0.7	2.3	0.3	5.9	9.3	2.5	5.0	45.0	0.5	0.6	1.7	5.7
1973	2	2125	90.6	5.7	0.4	3.2	0.3	3.4	9.6	2.6	4.7	46.1	0.4	0.6	2.3	6.3
1974	2	2083	88.2	7.3	0.6	3.9	0.4	3.5	10.0	1.9	4.4	46.0	1.0	0.5	3.0	5.3
1975	1	1930	86.6	7.6	1.0	4.7	0.6	3.2	8.5	2.0	4.7	48.2	1.1	0.4	1.0	4.6
1976	1	1886	88.5	6.3	0.6	4.6	0.0	5.0	9.1	1.6	6.0	47.0	1.1	0.2	2.0	5.0
1977	1	2097	88.3	6.2	0.7	4.8	0.4	4.6	8.4	1.1	6.1	49.3	1.1	0.4	2.0	5.2
TOTAL	2	16918	89.6	6.5	0.5	3.4	0.4	4.5	9.8	2.1	5.2	45.7	0.8	0.5	2.1	5.7
PRCNTL	.	69	93.2	17.7	28.5	44.9	4.1	8.8	2.8	2.0	66.0	73.5	91.2	3.4	78.2	23.0

COHORT	CSEC	EXFMR	OBFMR	ISFMR	SBFMR	ZFMR	EXNMR	OBNMR	ISNMR	SBNMR	ZNMR	EXPMR	OBPMR	ISPMR	SBPMR	ZPMR
1970	8.7	8.2	7.1	88.4	95.1	-0.7	10.2	11.4	111.2	102.4	0.7	18.2	18.4	101.3	100.5	0.1
1971	9.8	8.8	7.1	80.6	92.9	-0.9	12.3	9.9	80.4	95.0	-1.4	20.3	16.9	83.2	93.3	-1.5
1972	12.9	8.1	9.3	114.4	104.9	0.7	8.8	10.8	123.4	103.9	1.2	18.7	20.0	107.0	102.7	0.6
1973	13.4	8.3	5.6	68.3	89.4	-1.4	9.7	8.5	87.6	97.7	-0.7	17.6	14.1	80.0	92.0	-1.6
1974	17.1	8.6	6.7	77.9	92.3	-1.0	9.2	8.7	94.2	98.9	-0.3	17.3	15.4	88.8	95.9	-0.9
1975	19.5	5.2	6.2	118.8	104.1	0.6	5.9	6.2	105.1	100.5	0.2	18.7	12.4	116.2	103.3	0.9
1976	21.3	6.8	9.5	139.6	110.9	1.6	5.5	7.5	136.0	103.5	1.4	13.4	17.3	127.1	107.5	1.8
1977	21.9	6.5	5.7	88.2	96.7	-0.5	6.1	4.3	78.2	96.2	-1.4	12.4	10.8	80.6	94.7	-1.2
TOTAL	15.3	7.6	7.2	93.7	96.8	-0.8	8.6	8.5	99.8	99.4	-0.1	16.2	15.6	96.1	97.3	-0.8
PRCNTL	97.3	30.8	29.3	36.7	28.6	31.3	55.8	47.6	30.8	34.7	30.8	53.7	34.7	29.9	21.1	24.5

TABLE 9. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 13 BY HFPA OF OCCURRENCE
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

HFPA:1017 HFPANAME:SOUTH ORANGE COUNTY:ORANGE HSANAME:ORANGE COUNTY

COHORT	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	1	961	84.6	11.9	0.8	2.6	0.5	7.2	16.6	4.5	4.9	50.7	0.6	1.1	1.9	6.9
1971	1	859	86.6	10.4	0.5	2.5	0.3	5.8	15.3	2.2	4.4	44.5	0.6	1.4	1.4	6.3
1972	2	1352	83.3	12.2	1.4	3.1	0.6	4.8	11.3	3.5	5.5	44.3	0.4	0.7	1.7	6.7
1973	3	1387	84.9	10.8	2.2	2.2	0.6	4.1	12.3	3.4	4.4	45.4	0.7	0.8	1.9	7.2
1974	4	1715	82.7	11.9	3.1	2.4	1.3	5.7	11.1	3.4	4.5	43.1	0.5	0.6	1.6	6.5
1975	3	1664	82.4	12.0	1.6	3.3	0.7	5.2	9.5	4.1	4.8	44.6	0.4	0.5	2.0	5.5
1976	4	1650	83.5	12.0	1.8	2.6	1.0	5.3	9.9	2.1	4.8	41.0	0.5	0.8	1.0	5.9
1977	4	1773	84.1	10.9	1.5	3.6	0.9	5.2	10.5	2.0	6.4	43.4	0.9	0.4	1.0	4.2
TOTAL	4	11361	83.[illegible]	11.7	1.6	3.0	0.8	5.3	11.5	3.1	5.0	44.3	0.6	0.7	1.8	6.2
PRCNTL	.	63	76.9	44.2	40.1	36.7	10.9	10.9	11.6	5.4	58.5	64.6	83.8	15.8	34.8	38.8

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	11.1	10.2	9.4	91.5	98.1	-0.3	13.4	13.7	101.8	100.2	0.1	22.3	22.9	104.3	101.3	0.2
1971	11.2	8.3	7.8	84.4	97.4	-0.4	10.8	10.6	105.8	100.4	0.2	16.3	17.5	97.2	99.5	-0.1
1972	11.8	9.5	8.9	93.1	98.1	-0.3	10.6	9.7	91.8	98.9	-0.4	20.4	18.5	98.7	97.3	-0.6
1973	14.0	8.5	10.1	119.2	104.8	0.7	8.4	7.3	87.0	98.7	-0.5	17.7	17.3	97.9	99.5	-0.1
1974	16.6	8.4	8.2	97.4	99.2	-0.1	7.6	8.8	116.8	101.9	0.7	16.8	16.9	105.9	101.6	0.4
1975	17.3	6.1	4.2	69.4	93.2	-1.0	7.1	5.4	78.4	97.4	-1.0	12.7	9.6	75.7	94.7	-1.4
1976	19.3	5.7	3.8	53.3	90.6	-1.5	5.4	4.9	90.1	99.2	-0.3	11.3	7.9	71.5	94.9	-1.4
1977	21.0	5.3	3.4	64.0	92.4	-1.2	3.8	4.5	110.4	101.0	0.5	9.6	7.9	81.9	96.7	-0.9
TOTAL	16.2	7.5	6.4	86.1	92.6	-1.4	7.7	7.5	97.4	98.9	-0.3	15.2	13.9	91.6	95.3	-1.4
PRCNTL	99.3	33.3	18.4	23.8	13.6	10.4	34.7	24.5	35.4	31.3	34.7	32.7	15.8	10.4	15.8	16.3

HFPA:0030 HFPANAME:NONHOSPITAL SITES COUNTY:ORANGE HSANAME:ORANGE COUNTY

COHORT	NHOSP	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	0	96	68.9	27.4	0.9	2.8	34.9	14.3	10.2	3.9	9.7	27.4	1.0	10.4	2.0	16.2
1971	0	161	74.6	23.1	1.2	1.2	27.2	10.2	17.4	3.6	11.2	32.8	1.2	5.3	4.7	10.5
1972	0	220	74.6	23.3	0.4	1.7	19.4	10.9	20.3	4.3	5.7	30.4	0.4	3.0	0.9	5.9
1973	0	287	79.5	17.4	0.9	2.3	14.2	7.4	13.4	2.8	5.6	29.3	0.5	3.7	1.4	3.4
1974	0	225	76.3	20.3	1.2	2.1	14.5	7.2	19.6	0.8	3.3	36.5	0.4	2.5	0.0	3.5
1975	0	287	78.2	19.5	0.3	1.9	17.2	5.2	15.7	2.6	4.5	30.0	0.3	2.9	0.0	3.5
1976	0	489	81.0	16.6	1.4	1.0	12.5	8.1	17.2	2.4	6.9	35.3	0.6	4.0	1.0	4.1
1977	0	471	78.5	15.5	1.9	4.1	12.6	7.9	11.8	1.9	3.7	28.9	0.2	1.0	0.0	5.1
TOTAL	0	2156	77.7	18.9	1.1	2.2	16.4	8.2	15.0	2.5	5.7	33.5	0.4	3.3	1.0	5.3

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	0.0	25.0	10.4	40.4	95.4	-1.1	37.4	52.6	140.7	102.4	1.2	50.4	62.5	107.1	100.9	0.3
1971	0.6	12.9	12.4	96.0	99.0	-0.1	17.8	10.9	110.9	100.4	0.3	29.2	31.1	106.4	100.5	0.2
1972	0.0	10.6	13.6	120.3	101.9	0.5	15.1	10.4	122.4	101.1	0.6	27.9	31.0	114.1	101.5	0.3
1973	0.0	8.6	19.3	225.3	106.5	1.9	5.3	4.9	93.0	99.9	-0.1	17.6	24.2	137.1	102.2	1.0
1974	0.2	7.8	17.9	220.6	106.2	1.9	3.7	9.8	242.6	108.9	1.3	15.1	26.7	176.1	103.0	1.0
1975	0.0	5.0	3.5	69.2	98.7	-0.4	6.1	10.5	171.6	101.6	1.3	9.6	13.9	145.2	101.6	0.9
1976	0.3	5.3	2.8	30.2	95.9	-1.1	5.1	10.2	200.5	102.3	1.0	9.0	12.3	125.3	101.4	0.6
1977	0.0	6.7	10.6	159.0	105.3	1.1	6.2	4.3	69.3	99.1	-0.7	12.2	14.9	121.5	101.6	0.6
TOTAL	0.0	8.2	9.7	119.1	103.0	0.9	8.7	11.7	134.8	105.9	2.0	17.1	21.3	125.0	106.3	2.1

TABLE 10. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 13 BY HOSPITAL OF BIRTH
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

COUNTY:ORANGE NAME:ANAHEIM GENERAL HOSPITAL CITY:ANAHEIM CODE:373 HFPA:1012

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	974	87.4	11.3	0.3	1.0	0.1	7.6	13.3	3.9	4.2	44.3	0.1	0.0	1.4	7.5
1971	963	89.7	7.0	0.4	2.1	0.2	2.4	12.4	2.4	3.6	46.6	0.5	0.7	1.2	7.4
1972	673	90.0	10.2	0.4	1.3	0.3	3.7	11.0	2.0	4.4	45.3	0.9	0.6	2.1	7.3
1973	820	85.4	11.2	1.3	2.5	0.6	4.1	10.1	3.0	2.4	52.6	0.6	0.5	1.9	7.1
1974	1060	81.6	13.9	1.0	3.5	1.4	4.9	13.2	3.4	3.0	46.5	0.3	0.3	2.4	7.3
1975	1150	80.1	15.2	1.7	3.3	0.5	10.4	11.4	4.6	3.3	43.2	0.5	0.6	3.4	7.2
1976	1040	79.3	16.4	1.1	3.5	1.1	0.0	14.0	2.9	3.5	42.5	0.2	1.3	2.6	6.1
1977	896	77.6	17.7	1.3	3.7	0.0	12.2	14.7	3.7	3.3	43.4	0.3	0.9	1.6	5.0
TOTAL	7592	83.3	13.1	0.9	2.6	0.6	7.0	12.0	3.4	3.4	45.3	0.4	0.0	2.1	6.9
PRCNTL	73	81.6	34.9	28.3	40.4	14.1	19.7	30.6	12.9	10.4	76.0	46.7	17.5	75.5	63.5

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	3.6	7.9	0.2	103.3	101.0	0.1	9.3	10.4	111.5	102.5	0.4	16.0	10.5	110.2	103.2	0.5
1971	6.3	7.9	0.3	105.3	101.6	0.2	8.9	15.7	176.3	116.3	2.5	16.6	23.9	144.2	114.5	2.1
1972	7.0	9.6	10.4	100.1	102.3	0.2	9.1	12.0	132.3	105.6	1.3	20.7	22.3	137.5	102.7	0.4
1973	10.4	7.9	9.7	122.3	105.9	0.6	7.7	7.3	94.7	99.1	-0.2	16.0	16.9	100.9	100.3	0.0
1974	10.3	8.5	10.4	121.6	110.0	0.7	7.1	10.5	147.3	114.2	1.4	16.9	20.0	122.9	111.3	1.2
1975	12.3	6.2	7.0	112.2	104.7	0.3	7.1	10.5	147.7	115.9	1.6	13.7	17.4	126.0	111.6	1.2
1976	15.0	7.7	8.6	111.2	104.0	0.3	8.8	7.7	96.2	98.5	-0.1	14.9	16.2	109.1	104.1	0.4
1977	15.1	5.3	4.5	85.0	95.7	-0.3	4.3	4.5	104.9	100.6	0.1	9.4	8.9	95.4	90.0	-0.1
TOTAL	10.1	7.5	8.3	109.9	106.0	0.8	7.6	9.8	128.5	114.7	2.5	15.5	18.0	116.3	110.7	2.1
PRCNTL	56.0	30.5	49.9	64.6	73.9	70.5	35.0	66.9	84.1	90.3	95.9	41.3	62.4	75.3	92.1	80.9

COUNTY:ORANGE NAME:ANAHEIM MEMORIAL HOSPITAL CITY:ANAHEIM CODE:374 HFPA:1012

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	618	85.3	12.0	0.2	1.0	1.3	7.0	11.9	4.5	5.5	40.2	0.6	1.5	1.6	7.4
1971	625	86.6	11.7	0.5	1.3	1.6	6.6	14.6	5.4	4.2	45.4	0.5	1.1	1.6	5.3
1972	584	82.7	15.2	0.7	1.4	1.0	6.1	11.9	4.1	4.6	42.4	0.0	0.9	1.0	7.5
1973	566	80.3	16.9	1.1	1.0	0.9	7.3	6.3	4.2	4.3	44.4	0.5	1.2	2.1	7.9
1974	700	78.3	18.7	1.3	2.1	1.5	10.3	11.0	7.2	3.0	40.0	0.3	0.3	2.5	6.9
1975	726	76.6	19.4	0.0	3.2	2.2	13.6	13.7	6.5	2.1	49.9	0.1	0.0	1.7	7.0
1976	124	75.0	21.0	0.0	2.4	5.6	13.0	10.0	4.0	8.1	51.6	0.3	0.0	0.0	4.0
1977	2	50.0	25.0	0.0	25.0	25.0	25.0	33.3	0.0	0.0	25.0	0.0	0.0	0.0	33.3
TOTAL	3953	81.1	16.1	0.6	2.0	1.6	8.9	11.6	5.4	4.2	45.6	0.3	0.9	1.7	6.9
PRCNTL	53	75.3	46.3	24.9	23.0	49.2	31.3	10.0	36.7	23.7	78.2	41.3	27.4	34.5	63.3

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	5.0	5.1	9.7	106.7	101.6	0.2	12.1	9.0	80.0	95.0	-0.7	20.2	13.4	95.9	90.0	-0.2
1971	7.0	6.9	12.0	105.4	116.0	1.9	7.0	8.1	103.7	100.5	0.1	14.4	20.0	144.7	109.3	1.5
1972	8.6	11.0	12.0	109.1	102.6	0.3	11.4	13.9	121.6	104.2	0.7	24.2	25.7	106.2	102.3	0.3
1973	8.5	10.5	14.1	134.6	109.1	0.9	9.5	5.4	56.4	93.2	-1.2	20.6	19.4	94.2	90.3	-0.3
1974	6.7	0.3	6.5	100.2	102.1	0.2	5.6	7.1	127.7	104.0	0.6	15.2	15.5	102.4	100.0	0.1
1975	14.0	0.4	9.6	114.6	105.3	0.4	0.7	12.5	143.7	112.2	1.3	10.1	22.3	122.0	109.0	1.0
1976	11.3	4.3	0.1	109.7	103.7	0.7	3.1	0.0	0.0	98.2	-0.6	7.6	0.1	105.9	100.2	0.1
1977	0.0	34.6	0.0	0.0	99.4	-0.3	34.3	0.0	0.0	99.7	-0.3	66.6	0.0	0.0	99.5	-0.4
TOTAL	8.0	8.0	10.9	124.1	111.6	1.5	8.9	9.2	103.5	101.4	0.2	16.3	20.3	109.4	105.2	1.0
PRCNTL	34.0	60.9	79.4	79.1	80.2	83.9	63.0	59.6	56.5	59.0	55.1	71.2	72.3	66.9	74.8	69.6

COUNTY:ORANGE NAME:BIRTH CENTER CITY:SANTA ANA CODE:376 HFPA:1013

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1977	138	89.2	7.9	0.7	2.2	0.7	3.6	15.3	0.7	0.0	40.2	0.0	0.0	0.0	2.2
TOTAL	138	89.2	7.9	0.7	2.2	0.7	3.6	15.3	0.7	0.0	40.2	0.0	0.0	0.0	2.2

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1977	0.0	2.9	0.0	0.0	96.0	-0.6	2.1	0.0	0.0	98.6	-0.5	5.1	0.0	0.0	97.6	-0.8
TOTAL	0.0	2.9	0.0	0.0	99.1	-0.6	2.1	0.0	0.0	99.6	-0.5	5.1	0.0	0.0	99.2	-0.8

TABLE 18. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 13 BY HOSPITAL OF BIRTH
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

COUNTY:ORANGE NAME:CHAPMAN GENERAL HOSPITAL CITY:ORANGE CODE:377 HFPA:1815

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	826	83.7	13.0	0.7	1.0	0.7	6.5	12.6	4.2	3.0	43.7	0.6	1.4	2.4	7.0
1971	919	84.4	13.3	1.2	1.4	0.9	5.1	12.1	3.7	4.9	40.0	0.5	1.5	3.3	5.7
1972	862	81.9	15.0	0.0	1.5	0.3	3.4	11.0	3.5	3.6	40.0	0.2	1.3	1.9	6.1
1973	836	78.3	18.3	1.4	2.0	0.5	5.0	16.0	4.3	4.4	43.0	0.5	0.6	1.0	5.3
1974	774	74.1	22.4	0.0	2.7	0.4	6.5	12.7	4.5	3.4	42.1	0.4	0.6	3.0	6.0
1975	561	76.7	20.1	2.0	1.2	0.7	6.3	11.5	3.9	5.9	41.3	0.7	1.1	2.5	6.9
1976	500	73.0	20.2	1.0	4.2	1.4	0.9	9.5	4.4	4.0	43.0	0.3	0.6	1.2	6.0
1977	389	74.3	19.3	2.1	4.4	0.3	5.4	14.6	3.1	4.4	43.7	0.5	1.0	1.0	2.0
TOTAL	5667	79.2	17.4	1.2	2.2	0.6	5.0	12.6	4.0	4.2	42.3	0.4	1.0	2.1	6.0
PRCNTL	63	71.4	90.3	34.2	28.0	14.3	13.4	29.7	21.3	31.3	49.2	59.2	32.7	74.0	36.5

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	5.0	0.2	12.1	147.1	112.7	1.3	7.0	0.6	123.1	103.4	0.6	17.5	20.6	117.5	105.0	0.0
1971	6.1	6.3	14.1	223.3	120.5	3.1	6.7	3.3	49.7	92.6	-1.3	14.4	17.4	120.5	105.7	0.9
1972	0.4	7.7	7.0	90.0	97.2	-0.3	9.6	0.2	85.3	96.2	-0.6	15.3	15.1	90.7	99.6	-0.1
1973	10.9	0.2	0.4	101.0	100.5	0.1	10.2	9.7	94.9	90.7	-0.2	17.1	17.9	105.1	101.7	0.2
1974	10.4	9.0	14.2	145.1	119.0	1.4	0.9	5.2	39.1	86.3	-1.3	20.2	19.4	95.9	90.0	-0.2
1975	11.0	9.2	0.9	97.4	99.1	-0.1	0.0	10.0	122.5	100.2	0.6	10.7	19.6	105.1	102.1	0.2
1976	9.6	6.6	10.0	150.9	111.6	1.0	6.0	4.0	67.0	94.9	-0.6	12.5	14.0	111.7	102.6	0.3
1977	0.2	3.4	2.6	76.2	97.7	-0.3	2.4	0.0	0.0	95.0	-1.0	5.7	2.6	44.0	90.9	-0.0
TOTAL	0.5	7.7	10.2	133.3	117.9	2.4	7.0	6.6	64.2	92.5	-1.3	15.0	16.0	105.0	103.5	0.7
PRCNTL	39.7	42.4	74.0	64.1	96.6	93.9	41.3	20.0	28.4	12.5	16.1	46.9	52.2	60.1	60.0	63.3

COUNTY:ORANGE NAME:COSTA MESA MEMORIAL HOSPITAL CITY:COSTA MESA CODE:378 HFPA:1816

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	2	50.0	50.0	0.0	0.0	0.0	0.0	100.0	0.0	0.0	50.0	0.0	0.0	0.0	50.0
1971	1	0.0	0.0	0.0	100.0	0.0	0.0	.	0.0	100.0	100.0	100.0	0.0	0.0	0.0
1973	1	100.0	0.0	0.0	0.0	0.0	0.0	.	0.0	0.0	100.0	0.0	0.0	0.0	0.0
1974	1	0.0	0.0	100.0	0.0	0.0	100.0	.	0.0	0.0	100.0	0.0	0.0	0.0	0.0
TOTAL	5	40.0	20.0	20.0	20.0	0.0	20.0	100.0	0.0	20.0	80.0	20.0	0.0	0.0	20.0

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	0.0	26.5	0.0	0.0	99.7	-0.2	19.7	0.0	0.0	99.9	-0.2	45.3	0.0	0.0	99.8	-0.3
1971	0.0	.	0.0	.	.	.	3.3	0.0	0.0	100.0	-0.1	3.3	0.0	0.0	100.0	-0.1
1973	0.0	2.2	0.0	0.0	100.0	-0.0	1.9	0.0	0.0	100.0	-0.0	4.0	0.0	0.0	100.0	-0.1
1974	0.0	1.0	0.0	0.0	100.0	-0.0	2.3	0.0	0.0	100.0	-0.0	4.1	0.0	0.0	100.0	-0.1
TOTAL	0.0	11.4	0.0	0.0	99.9	-0.2	5.4	0.0	0.0	99.9	-0.2	20.4	0.0	0.0	99.9	-0.3

COUNTY:ORANGE NAME:ESPERANZA INTERCOMM. HOSP. CITY:YORBA LINDA CODE:381 HFPA:1811

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1974	8	75.0	25.0	0.0	0.0	0.0	12.5	20.0	25.0	0.0	37.5	0.0	0.0	25.0	0.0
1976	1	100.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
1977	35	74.3	20.0	0.0	5.7	0.0	8.6	0.0	2.9	8.6	45.7	0.0	2.9	0.0	2.9
TOTAL	44	75.0	20.5	0.0	4.5	0.0	9.1	4.0	6.8	6.8	43.2	0.0	2.3	4.5	2.3
PRCNTL	8	61.0	56.2	2.7	65.5	0.7	32.9	0.2	54.4	65.9	56.7	9.5	70.3	99.3	8.5

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1974	0.0	4.1	0.0	0.0	99.7	-0.2	3.5	0.0	0.0	99.9	-0.2	7.6	0.0	0.0	99.8	-0.2
1976	0.0	4.2	0.0	0.0	100.0	-0.1	3.2	0.0	0.0	100.0	-0.1	7.3	0.0	0.0	100.0	-0.1
1977	22.9	3.1	0.0	0.0	99.1	-0.3	2.1	0.0	0.0	99.7	-0.3	5.2	0.0	0.0	99.4	-0.4
TOTAL	18.2	3.3	0.0	0.0	99.7	-0.4	2.4	0.0	0.0	99.9	-0.3	5.7	0.0	0.0	99.7	-0.5
PRCNTL	90.9	0.2	2.3	2.3	47.4	37.4	0.2	2.7	2.7	46.7	36.3	0.2	0.9	0.9	42.9	33.3

COUNTY:ORANGE NAME:FOUNTAIN VALLEY COMMUNITY HOSPITAL CITY:FOUNTAIN VALLEY CODE:382 HFPA:1814

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1974	672	81.2	12.6	3.0	3.3	1.2	10.6	11.7	6.4	5.6	37.9	0.4	1.9	1.2	7.3
1975	1569	60.9	22.0	3.9	4.4	5.7	9.7	11.2	4.9	5.4	42.3	0.3	1.4	1.9	6.3
1976	1246	82.7	11.0	1.4	4.2	1.4	5.6	11.4	2.9	4.5	42.5	0.4	0.0	2.7	6.1
1977	1297	77.0	16.3	1.3	6.0	2.2	5.6	11.9	2.2	4.6	42.1	0.3	0.4	2.2	6.3
TOTAL	4784	76.4	16.6	2.3	4.6	3.3	7.7	11.5	3.8	5.0	41.7	0.4	1.0	2.1	6.4
PRCNTL	59	64.9	47.6	45.1	66.2	74.1	24.7	17.2	19.3	31.7	48.5	45.4	34.8	70.3	47.6

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1974	11.4	0.0	0.9	101.9	100.7	0.0	7.3	12.0	163.2	114.9	1.6	16.6	20.0	125.0	109.5	1.0
1975	13.9	6.3	7.2	112.2	105.6	3.4	6.2	5.1	82.7	93.4	-0.6	12.3	12.1	98.2	99.1	-0.1
1976	13.0	7.1	4.0	60.1	85.5	-1.3	6.7	9.7	143.6	116.0	1.6	13.6	14.4	108.4	103.1	0.3
1977	16.4	7.0	7.7	90.0	99.4	-0.6	5.0	3.9	66.6	80.0	-1.1	14.7	11.6	78.4	88.6	-1.2
TOTAL	14.2	7.2	6.9	95.3	97.7	-0.3	6.4	6.9	100.7	103.2	0.6	13.9	13.0	99.2	99.6	-0.1
PRCNTL	80.7	25.4	31.1	40.4	37.0	40.4	15.2	24.9	64.4	65.0	64.9	10.6	22.4	43.3	41.5	42.6

TABLE 18. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 13 BY HOSPITAL OF BIRTH
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

COUNTY:ORANGE NAME:GARDEN PARK GENERAL HOSPITAL CITY:ANAHEIM CODE:385 HFPA:1012

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	804	86.1	11.4	0.2	2.6	0.5	11.2	11.9	4.7	5.3	43.9	3.3	1.7	2.5	8.3
1971	715	84.7	13.4	0.3	1.9	0.3	5.7	11.8	3.6	5.7	43.4	0.3	1.1	1.9	6.4
1972	734	84.6	13.5	0.1	1.8	1.3	5.2	14.9	3.5	4.4	44.4	0.4	0.7	1.4	6.9
1973	641	81.4	16.1	0.9	1.6	1.9	8.2	11.8	6.9	6.4	44.5	0.6	1.2	3.1	7.6
1974	659	79.7	17.2	0.6	2.6	1.1	8.2	12.5	3.9	3.6	44.7	0.3	0.9	4.4	6.9
1975	581	73.0	22.4	0.9	3.7	0.5	10.4	14.8	5.0	3.6	45.4	0.5	0.4	2.5	6.1
1976	85	83.5	14.1	0.0	2.4	1.2	7.1	7.0	2.4	1.2	49.4	0.0	0.0	2.4	2.4
TOTAL	4199	82.1	15.1	0.5	2.3	0.9	8.1	12.5	4.5	4.7	44.4	0.5	1.0	2.8	7.0
PRCNTL	55	78.9	41.5	16.6	32.9	20.2	26.3	29.0	27.9	44.4	68.9	68.5	32.4	95.7	64.9

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	6.3	10.4	12.4	119.0	100.6	0.6	9.3	7.6	81.0	96.4	-0.6	22.5	19.9	80.4	95.1	-0.7
1971	6.7	9.3	5.6	60.2	80.9	-1.1	12.7	10.3	143.7	112.0	1.0	20.1	23.0	110.6	106.6	0.9
1972	9.1	7.6	4.1	53.6	89.0	-1.2	7.2	4.1	38.6	94.0	-1.1	13.4	8.2	53.2	87.7	-1.9
1973	11.7	9.1	7.0	80.9	96.4	-0.4	11.4	14.2	124.0	105.9	0.9	19.2	21.0	114.0	104.5	0.6
1974	15.2	6.4	6.1	95.2	98.7	-0.1	7.4	12.2	165.6	113.7	1.7	13.0	10.2	140.6	111.5	1.4
1975	18.1	6.6	7.1	108.4	102.1	0.2	6.2	9.0	145.3	100.6	1.0	13.3	16.0	121.2	105.0	0.7
1976	23.5	4.6	11.0	234.9	104.9	1.0	3.2	0.0	0.0	90.7	-0.5	7.7	11.0	153.4	101.3	0.4
TOTAL	11.0	8.3	7.4	89.4	94.8	-0.7	9.0	10.6	117.2	107.6	1.3	17.3	17.5	103.3	101.9	0.4
PRCNTL	67.6	57.0	38.3	32.4	27.2	38.6	64.9	75.3	74.0	86.4	81.0	63.0	61.7	53.5	54.9	52.6

COUNTY:ORANGE NAME:HOAG MEMORIAL HOSPITAL CITY:NEWPORT BEACH CODE:387 HFPA:1016

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	2390	92.3	5.7	0.2	1.8	0.5	6.2	11.5	2.7	5.4	40.5	0.6	0.5	2.0	6.4
1971	2240	91.0	6.6	0.2	2.2	0.2	4.1	11.0	2.5	5.3	43.1	0.0	0.6	2.0	6.6
1972	2149	90.5	6.5	0.7	2.3	0.3	5.9	9.3	2.5	5.8	45.0	0.5	0.6	1.7	5.7
1973	2124	90.6	5.7	0.4	3.2	0.3	3.4	9.6	2.6	4.8	46.1	0.4	0.6	2.3	6.3
1974	2082	88.3	7.3	0.5	3.9	0.4	3.4	10.0	1.9	4.4	46.7	1.0	0.5	3.0	5.3
1975	1930	86.6	7.6	1.0	4.7	0.6	3.2	8.5	2.0	4.7	48.2	1.1	0.4	1.8	4.6
1976	1865	88.5	6.3	0.6	4.6	0.0	5.0	9.1	1.6	6.0	47.0	1.1	0.2	2.8	5.0
1977	2097	88.3	6.2	0.7	4.8	0.4	4.6	8.4	1.1	6.1	49.3	1.1	0.4	2.0	5.2
TOTAL	16813	89.6	6.5	0.5	3.4	0.4	4.5	9.8	2.1	5.2	45.7	0.8	0.5	2.1	5.7
PRCNTL	93	94.6	12.8	19.5	52.6	6.3	8.8	5.0	4.8	59.9	78.7	86.2	4.5	71.4	24.3

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	8.7	8.2	7.1	86.6	93.0	-0.6	10.2	11.4	111.4	105.4	0.7	18.1	18.4	101.6	100.9	0.1
1971	9.8	8.8	7.1	80.6	89.7	-0.9	12.3	9.9	88.4	89.5	-1.4	20.3	16.9	83.2	89.3	-1.3
1972	12.9	8.1	9.3	114.4	107.2	0.7	8.8	10.8	123.4	109.5	1.2	18.7	20.8	107.0	104.3	0.6
1973	13.4	8.3	5.6	60.3	84.2	-1.4	9.7	8.5	87.6	94.5	-0.7	17.6	14.1	80.8	88.4	-1.6
1974	17.1	8.6	6.7	78.8	85.9	-1.8	9.2	8.7	94.2	98.4	-0.3	17.3	15.4	88.8	92.3	-0.9
1975	19.3	9.2	6.2	118.8	109.8	0.6	5.9	6.2	105.1	102.1	0.2	18.7	12.4	116.2	108.0	0.9
1976	21.3	6.8	9.5	139.6	122.1	1.6	5.3	7.5	136.8	115.3	1.4	13.4	17.0	127.1	116.2	1.8
1977	21.9	6.5	5.7	80.2	93.3	-0.5	6.1	4.3	70.2	85.2	-1.4	12.4	10.3	80.6	88.5	-1.2
TOTAL	15.3	7.6	7.2	93.7	98.1	-0.8	8.6	8.5	99.1	99.3	-0.1	16.2	15.6	96.2	96.8	-0.8
PRCNTL	93.2	40.8	34.7	39.0	30.1	27.7	36.0	40.5	45.1	40.1	42.0	52.4	39.5	35.4	26.8	26.8

COUNTY:ORANGE NAME:HUNTINGTON INTERCOMMUNITY HOSP. CITY:HUNTINGTON BEACH CODE:388 HFPA:1014

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	1000	89.6	7.8	0.1	2.5	2.1	6.5	11.0	5.0	5.0	35.1	0.3	1.3	3.1	7.2
1971	960	90.0	6.2	0.1	3.7	6.4	5.1	9.9	3.8	6.4	34.8	0.7	0.9	1.1	6.8
1972	957	87.1	8.4	0.3	4.1	3.7	6.3	11.4	4.7	4.8	38.4	0.6	0.7	2.7	6.5
1973	1400	82.7	12.8	0.6	3.9	0.1	0.4	9.9	3.9	5.3	35.9	0.1	0.9	2.6	5.8
1974	1281	83.6	11.3	1.0	4.1	4.7	6.9	10.0	2.4	5.7	40.7	1.0	1.2	1.2	5.2
1975	904	86.1	9.4	0.6	4.0	0.6	6.6	10.2	3.3	3.9	41.5	0.2	0.4	2.3	4.3
1976	716	83.3	9.2	1.0	6.5	0.6	5.7	10.4	1.9	5.1	41.3	1.1	1.3	3.6	5.4
1977	1004	80.7	12.8	1.2	5.2	11.9	14.3	12.1	4.2	4.4	47.4	0.4	0.6	2.2	5.5
TOTAL	8120	85.3	9.9	0.6	4.3	6.7	7.6	10.7	3.6	5.2	39.1	0.6	0.9	2.3	5.9
PRCNTL	77	85.7	24.5	28.9	62.0	91.4	24.3	10.7	10.3	59.2	20.6	72.1	25.2	86.8	31.1

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	10.6	8.8	4.6	52.3	83.3	-1.6	12.8	11.1	86.9	95.0	-0.7	19.7	15.6	79.2	90.6	-1.3
1971	10.2	7.1	6.9	97.1	99.3	-0.1	8.2	7.0	84.8	97.1	-0.5	15.1	13.0	91.7	97.6	-0.4
1972	10.9	7.3	8.4	114.7	104.1	0.4	8.0	6.3	72.1	93.9	-1.0	15.1	14.6	96.6	98.9	-0.2
1973	10.9	7.4	5.3	67.3	88.2	-1.1	8.3	4.3	52.1	84.9	-2.1	15.1	9.3	61.4	84.8	-2.2
1974	12.3	6.6	3.3	50.3	79.3	-1.3	6.5	5.3	77.2	92.5	-0.7	12.3	8.3	67.6	87.3	-1.4
1975	12.7	6.4	6.6	104.1	101.5	0.1	7.9	8.9	113.5	104.6	0.4	13.4	15.5	115.3	106.1	0.7
1976	17.5	7.2	2.8	30.9	80.0	-1.5	9.9	8.4	84.6	93.5	-0.6	15.2	11.2	73.3	89.0	-1.2
1977	10.7	6.2	3.8	80.6	93.3	-0.5	5.9	6.3	101.9	100.5	0.1	11.4	11.0	95.9	98.5	-0.2
TOTAL	12.7	7.1	5.3	74.8	84.3	-2.1	8.5	6.9	81.7	89.3	-1.9	14.7	12.2	82.0	88.5	-2.3
PRCNTL	79.6	21.5	10.2	12.9	3.3	6.3	54.2	24.7	17.2	5.2	6.3	20.6	11.1	12.2	5.2	7.3

TABLE 10. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 13 BY HOSPITAL OF BIRTH
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

COUNTY:ORANGE NAME:LA PAZ MEDICAL CENTER CITY:MISSION VIEJO CODE:389 HFPA:1017

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	HOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1974	52	54.5	18.2	27.3	0.0	20.0	43.6	19.4	7.3	5.5	32.1	0.0	1.9	3.6	16.7
1976	2	100.0	0.0	0.0	0.0	0.0	0.0	0.0	50.0	0.0	50.0	0.0	0.0	50.0	0.0
1977	1	0.0	100.0	0.0	0.0	0.0	100.0	.	0.0	0.0	100.0	0.0	0.0	0.0	0.0
TOTAL	55	55.2	19.0	25.9	0.0	19.0	43.1	18.9	8.6	5.2	33.9	0.0	1.8	5.2	15.8
PRCNTL	1	34.5	53.1	92.5	8.9	99.3	97.1	80.7	73.7	57.8	3.2	9.5	62.4	99.8	99.8

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXMMR	OBMMR	ISMMR	BSMMR	ZMMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1974	14.5	6.0	0.0	0.0	97.5	-0.6	4.4	0.0	0.0	98.9	-0.5	10.3	0.0	0.0	98.1	-0.7
1976	0.0	4.2	-0.0	0.0	99.9	-0.1	1.6	0.0	0.0	100.0	-0.1	5.0	0.0	0.0	100.0	-0.1
1977	0.0	7.0	0.0	0.0	99.9	-0.1	2.9	0.0	0.0	100.0	-0.1	9.9	0.0	0.0	100.0	-0.1
TOTAL	13.8	5.9	0.0	0.0	99.3	-0.6	4.3	0.0	0.0	99.7	-0.5	10.1	0.0	0.0	99.4	-0.8
PRCNTL	86.4	6.6	2.3	2.3	44.7	32.9	2.7	2.7	2.7	44.2	32.4	2.5	8.9	8.9	40.6	27.4

COUNTY:ORANGE NAME:LOS ALAMITOS GENERAL HOSPITAL CITY:LOS ALAMITOS CODE:391 HFPA:1013

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	HOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	298	81.7	15.0	0.7	2.7	1.3	11.1	15.0	7.0	5.0	38.7	0.3	4.7	2.7	9.1
1971	406	76.5	19.4	1.5	2.7	2.0	15.1	13.4	5.4	6.1	41.4	0.2	2.7	2.5	6.9
1972	277	80.5	15.9	0.7	2.9	1.1	9.9	13.6	7.9	5.4	44.4	0.4	1.1	2.2	8.3
1973	346	80.7	12.9	0.9	5.5	3.2	12.0	9.7	9.5	4.9	40.8	0.6	1.4	3.2	5.8
1974	357	81.8	13.7	1.1	3.4	1.7	4.8	8.9	4.5	5.0	40.1	0.6	0.3	1.1	4.2
1975	406	79.3	13.5	1.7	5.4	3.0	6.2	12.0	4.2	4.7	40.1	0.2	0.5	2.5	5.4
1976	430	78.6	14.0	0.7	6.7	2.1	5.9	10.1	3.3	4.7	47.2	1.4	0.5	1.4	8.1
1977	413	75.4	17.9	1.4	5.3	3.6	9.1	11.0	3.4	5.6	49.3	0.5	0.5	2.7	4.8
TOTAL	2933	79.1	15.2	1.1	4.5	2.3	9.2	11.8	5.4	5.2	43.8	0.5	1.4	2.2	6.5
PRCNTL	44	78.5	42.4	32.4	64.6	64.9	33.3	28.9	37.2	57.6	54.9	71.4	47.4	83.2	49.4

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXMMR	OBMMR	ISMMR	BSMMR	ZMMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	6.3	14.2	13.4	94.2	98.8	-0.1	11.7	10.2	87.5	98.7	-0.3	29.3	23.5	88.2	94.4	-0.8
1971	7.0	9.3	12.3	132.9	105.8	0.7	8.5	7.3	87.9	98.8	-0.3	28.2	19.7	97.6	99.4	-0.1
1972	9.7	7.9	10.1	229.5	113.2	2.0	10.0	11.0	110.6	101.1	0.2	19.9	20.9	145.0	107.4	1.3
1973	16.7	7.2	14.5	200.0	111.6	1.7	12.4	14.7	110.0	102.9	0.5	19.1	20.9	151.3	109.9	1.7
1974	14.0	6.4	5.6	87.4	97.9	-0.2	5.5	8.5	153.3	105.3	0.0	11.7	14.0	119.0	103.1	0.5
1975	14.8	4.5	9.9	219.5	115.6	1.6	4.3	10.0	230.2	110.2	1.7	9.1	19.7	217.4	114.2	2.3
1976	24.7	9.2	14.8	151.4	114.7	1.1	3.9	7.1	182.3	106.2	1.1	10.0	20.9	116.5	105.5	0.6
1977	24.2	6.7	14.5	217.9	124.0	2.1	6.4	4.9	76.2	95.9	-0.5	13.2	19.4	146.6	118.9	1.4
TOTAL	15.5	8.3	12.6	157.4	122.2	3.0	7.5	9.0	119.5	105.9	1.1	17.1	21.5	125.0	112.3	2.3
PRCNTL	93.9	51.0	90.0	92.1	90.0	96.6	32.4	55.8	77.1	81.0	75.7	61.0	80.7	85.7	94.1	91.8

COUNTY:ORANGE NAME:MARTIN LUTHER HOSPITAL CITY:ANAHEIM CODE:392 HFPA:1012

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	HOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	1059	90.1	5.4	0.5	2.0	1.2	9.5	11.1	4.1	6.0	40.0	0.6	1.1	2.7	7.3
1971	785	88.0	10.9	0.1	0.9	2.4	5.5	11.4	2.7	5.2	37.4	0.3	1.0	1.5	6.0
1972	677	88.2	10.5	0.1	1.2	1.5	6.4	10.7	3.7	4.4	40.7	0.4	0.7	2.9	6.2
1973	563	85.6	11.9	0.2	2.3	0.7	6.3	11.6	2.3	2.7	38.5	0.2	0.2	3.2	8.5
1974	483	83.9	12.4	1.2	2.5	3.3	8.3	8.9	4.7	3.9	44.5	0.2	0.4	2.9	8.0
1975	421	78.1	18.9	1.2	1.9	6.1	11.4	9.5	6.0	2.8	42.9	0.2	0.5	1.9	5.7
1976	1720	74.7	19.7	1.3	4.4	2.7	10.7	10.9	4.8	3.7	40.2	0.6	0.6	1.9	5.5
1977	2065	74.3	20.4	1.3	4.0	1.9	14.6	12.6	5.2	4.3	47.7	0.4	0.4	1.4	4.5
TOTAL	7773	80.5	15.7	0.9	2.9	2.2	10.2	11.3	4.3	4.3	43.7	0.4	0.6	2.1	6.0
PRCNTL	75	73.9	44.0	27.4	47.8	63.5	39.7	16.1	24.3	32.4	61.2	58.0	18.9	70.7	35.1

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXMMR	OBMMR	ISMMR	BSMMR	ZMMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	8.1	8.5	7.6	80.7	96.3	-0.4	10.0	13.3	132.0	100.3	1.2	19.0	20.0	109.4	103.0	0.5
1971	10.1	8.5	1.3	14.9	76.4	-2.4	11.3	12.0	112.6	107.2	0.5	17.9	14.2	78.1	92.3	-1.0
1972	12.4	9.4	7.4	78.3	94.2	-0.6	13.0	16.4	125.4	107.3	1.3	21.7	23.6	100.7	103.2	2.4
1973	13.7	10.0	12.4	124.1	109.7	0.6	12.0	10.0	89.0	97.9	-0.3	22.5	23.1	102.5	100.8	2.1
1974	16.5	11.1	4.1	37.3	77.8	-1.7	13.0	16.6	120.6	100.0	0.0	20.0	20.7	99.4	99.0	-0.3
1975	22.6	5.4	4.0	80.7	90.2	-0.2	5.5	0.0	0.0	89.7	-1.6	10.6	4.0	44.9	91.3	-1.2
1976	15.0	6.0	7.6	111.6	100.1	0.4	5.6	8.2	147.0	117.2	1.6	13.2	15.7	110.9	110.3	1.1
1977	10.2	6.0	6.0	113.4	107.1	0.5	3.3	3.9	73.0	99.0	-1.0	11.1	10.7	95.9	97.0	-0.2
TOTAL	14.0	7.6	6.7	87.6	92.4	-1.0	8.3	9.2	118.7	106.1	1.3	15.7	15.0	101.0	100.7	0.1
PRCNTL	91.4	41.0	26.5	20.6	19.5	22.2	52.6	39.4	87.3	81.9	74.0	43.3	41.3	40.3	49.9	49.2

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                TABLE 18. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 13 BY HOSPITAL OF BIRTH
          SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA        155
 ———— COUNTY:ORANGE   NAME:MERCY GENERAL HOSPITAL   CITY:SANTA ANA   CODE:353   HFPA:1815 ————
COHORT BIRTH WHITE SPAN BLACK OTHER NOPRE OUTWED SHORT TEEN OLDER PARA1 OPARA1 PARA6 MULT LOBW
1974     742  24.5  69.5   4.6   1.5   1.7   8.9  16.9   5.1   5.6  44.5   0.9   3.9  1.9  4.5
1975     935  21.5  73.3   2.8   2.4   0.4   7.9  20.5   4.8   5.6  47.6   0.7   3.8  1.2  5.3
1976    1011  17.1  79.2   1.7   2.3   1.3   6.5  15.3   4.6   9.1  41.9   1.4   3.3  1.2  3.8
1977     995  14.8  81.7   1.8   1.7   3.5   8.9  14.9   5.5   5.3  46.2   0.5   3.8  1.6  5.9
TOTAL   3583  19.3  76.5   2.6   1.9   1.8   8.0  16.7   5.0   6.6  45.0   0.9   3.6  1.4  4.9
PRCNTL    49   6.6  97.7  47.4  22.9  54.9  25.6  69.4  32.2  83.7  73.5  69.1  85.9 17.7  8.2
COHORT CSEC EXFMR OBFMR ISFMR BBFMR ZFMR EXNMR OBNMR ISNMR BBNMR ZNMR EXPMR OBPMR ISPMR BBPMR ZPMR
1974   16.8   0.0   4.8  50.3  82.3 -1.3   7.4   6.6  91.6  97.7 -0.2  14.5  10.0  74.3  91.0 -1.0
1975   19.1   7.8   9.6 137.3 112.9  1.0   3.6   3.6 100.7 100.1  0.0  10.9  13.2 120.6 106.1  0.7
1976   17.5   6.9   6.9  97.8  99.9 -0.8   6.2   5.3  80.0  93.8 -0.6  12.3  11.9  96.3  90.5 -0.2
1977   21.6   7.2  10.1 139.8 115.7  1.1   5.2   7.1 135.5 100.6  0.9  12.7  17.1 134.1 113.4  1.5
TOTAL  18.9   7.3   7.8 107.7 103.1  0.4   5.6   5.6 101.8 100.3  3.1  12.6  13.4 106.6 102.0  0.5
PRCNTL 99.5  26.1  44.4  61.2  62.4 55.6   7.5  12.8  50.1  49.7 49.4   9.8  20.0  61.9  62.0 58.5
 —— COUNTY:ORANGE   NAME:MISSION COMMUNITY HOSPITAL   CITY:MISSION VIEJO   CODE:354   HFPA:1817 ——
COHORT BIRTH WHITE SPAN BLACK OTHER NOPRE OUTWED SHORT TEEN OLDER PARA1 OPARA1 PARA6 MULT LOBW
1972     740  87.3   8.2   1.9   2.7   0.5   3.6  10.1   2.8   5.2  41.7   0.3   0.4  2.5  6.1
1973     512  90.4   6.6   0.8   2.1   0.4   2.6   8.9   1.0   4.9  36.3   1.0   0.4  1.9  6.0
1974     669  89.4   7.2   1.2   2.2   0.3   3.2   9.0   2.2   4.9  37.3   0.4   0.4  2.4  5.7
1975     750  89.2   7.0   1.1   2.0   0.3   3.9   7.5   2.0   4.0  38.4   0.4   0.4  2.5  5.1
1976     709  87.5   8.2   0.4   4.1   0.6   1.3   7.2   0.4   3.7  35.0   0.3   0.7  1.7  6.0
1977     800  87.7   7.7   0.7   3.9   0.7   3.4   8.4   0.9   6.7  40.3   0.0   0.5  2.0  4.3
TOTAL   4260  88.5   7.5   1.0   3.0   0.5   3.0   8.5   1.7   5.1  38.5   0.5   0.5  2.2  5.6
PRCNTL    56  91.0  15.6  38.2  49.4   7.3   4.5   1.6   1.0  55.3  16.1  69.4   4.3 80.3 20.9
COHORT CSEC EXFMR OBFMR ISFMR BBFMR ZFMR EXNMR OBNMR ISNMR BBNMR ZNMR EXPMR OBPMR ISPMR BBPMR ZPMR
1972   11.8   7.6   6.7  80.5  97.3 -0.3   7.0   0.1 103.3 100.5  0.1  17.0  14.7  86.6  96.1 -0.6
1973   14.8   8.2   9.8 119.5 103.0  0.4   7.9   3.9  49.8  94.2 -1.2  16.4  13.7  83.3  96.2 -0.6
1974   13.4   7.2   7.5 103.7 101.1  0.1   6.5   6.0  32.7  90.4 -0.2  14.0  13.5  96.3  90.8 -0.1
1975    7.7   5.4   5.3  99.6  99.9 -0.8   6.6   2.7  40.4  84.0 -1.7  11.0   9.0  60.2  90.8 -1.1
1976   13.0   6.2   4.2  60.3  90.9 -0.7   5.4   7.1 131.6 105.0  0.7  12.1  11.3  93.4  90.3 -0.2
1977   21.0   3.5   0.0   0.0  80.0 -1.0   2.6   0.0   0.0  90.1 -1.5   6.1   8.8   0.0  83.8 -2.3
TOTAL  17.0   6.1   5.2  84.2  93.6 -0.9   5.9   4.5  73.4  92.4 -1.4  12.5   9.6  77.1  89.6 -2.0
PRCNTL 90.8   7.9   9.5  23.4  23.6 25.6  11.1   6.6  10.9  11.8 13.0   9.5   4.5   6.6   7.5  9.5
 —— COUNTY:ORANGE   NAME:PALM HARBOR GENERAL HOSPITAL   CITY:GARDEN GROVE   CODE:395   HFPA:1812 ——
COHORT BIRTH WHITE SPAN BLACK OTHER NOPRE OUTWED SHORT TEEN OLDER PARA1 OPARA1 PARA6 MULT LOBW
1970    1069  86.8   8.5   2.1   2.6   0.3   7.4  12.4   6.4   5.1  41.5   0.2   2.1  2.7  7.7
1971     921  85.6   9.8   2.4   3.0   0.3   7.4  12.7   5.4   5.3  44.0   0.6   1.3  1.3  5.3
1972     938  84.8   9.7   2.8   3.5   0.6   8.8  13.2   5.6   5.3  42.2   0.3   1.9  1.5  5.5
1973    1011  81.5  11.4   2.9   4.2   1.6  10.6  13.3   6.4   3.1  47.4   0.3   0.7  2.4  7.3
1974    1290  79.8  13.6   3.9   3.5   1.0  12.6  13.9   5.7   3.5  43.9   0.4   0.8  1.4  5.9
1975    1241  75.2  18.2   3.1   3.4   1.2  14.6  12.9   5.6   4.2  43.0   0.4   1.2  3.0  5.9
1976    1111  77.5  15.8   2.2   4.5   0.9  11.4  15.5   3.8   3.9  40.2   0.4   0.8  2.0  4.8
1977     821  75.6  18.5   2.6   3.4   0.7   9.8  10.2   2.4   5.3  40.6   0.7   1.3  1.7  3.9
TOTAL   8402  80.6  13.2   2.7   3.5   0.9  10.4  13.1   5.1   4.4  43.0   0.4   1.2  2.0  5.0
PRCNTL    78  74.1  35.1  40.5  53.5  19.7  40.6  37.0  33.6  35.1  55.1  53.7  43.0 63.0 30.0
COHORT CSEC EXFMR OBFMR ISFMR BBFMR ZFMR EXNMR OBNMR ISNMR BBNMR ZNMR EXPMR OBPMR ISPMR BBPMR ZPMR
1970    6.9   9.7   5.8  57.6  84.5 -1.5  13.2  15.1 113.8 104.6  0.6  21.9  23.6  93.9  97.3 -0.4
1971    8.5   7.9  11.9 150.3 115.1  1.5   7.8   5.5  70.5  93.6 -1.0  16.3  17.4 106.4 102.3  0.3
1972    9.2   7.8  10.7 136.4 111.1  1.1   7.7   8.6 111.5 102.5  0.4  16.1  19.2 119.8 106.9  1.3
1973    8.7   9.8  12.9 130.7 111.3  1.1   8.1   7.3  86.9  97.5 -0.4  20.1  19.8  90.6  99.4 -0.1
1974   10.5   8.2   7.8  94.5  97.2 -0.2   7.6   7.0 103.3 101.4  3.1  16.4  15.5  94.8  97.1 -0.3
1975   11.9   6.0   6.4  95.3  97.9 -0.1   7.1   6.5  92.3  97.8 -0.3  13.4  12.9  96.3  90.3 -0.2
1976   13.3   5.5   9.3 164.7 122.5  1.7   4.2   4.5 107.3 101.4  3.2  10.8  13.5 135.1 111.3  1.3
1977   14.8   5.9   9.7 165.6 120.2  1.5   4.1   3.7  89.9  90.4 -0.2  12.2  13.4 109.5 103.5  0.4
TOTAL  10.2   7.7   9.3 117.1 110.5  1.5   7.5   7.4  90.8  99.3 -0.1  15.8  16.4 104.8 102.8  0.6
PRCNTL 56.7  44.2  62.4  72.6  86.6 83.2  34.8  31.7  44.2  40.4 42.9  45.8  47.6  56.8  63.3 59.6
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TABLE 18. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 13 BY HOSPITAL OF BIRTH 156
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

——— COUNTY:ORANGE NAME:RIVERVIEW HOSPITAL CITY:SANTA ANA CODE:396 HFPA:1812 ———

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	391	63.9	30.6	2.3	3.5	0.8	12.5	18.7	6.3	8.3	32.6	0.3	4.3	4.8	9.1
1971	314	69.7	23.2	3.5	3.5	0.7	12.8	16.4	6.7	6.7	35.8	0.3	3.5	3.6	6.4
1972	345	66.4	28.7	2.9	2.8	0.3	20.7	15.4	7.8	4.1	35.9	0.3	2.3	0.6	5.8
1973	271	66.4	25.8	4.8	3.3	0.7	23.3	9.6	9.6	4.1	46.1	0.3	3.0	1.5	7.7
1974	252	52.2	35.6	7.5	4.7	1.2	25.7	21.8	12.3	4.3	47.4	0.3	2.4	4.0	13.4
1975	279	43.7	45.1	7.8	4.2	1.1	21.8	17.1	12.3	6.3	46.5	0.4	2.5	1.4	7.1
1976	377	43.8	45.1	5.5	5.5	0.5	29.5	23.3	13.2	4.2	54.6	0.3	1.0	0.5	5.8
1977	424	43.8	47.1	4.9	5.2	1.4	34.3	18.3	11.3	3.3	51.1	0.5	1.2	2.8	7.3
TOTAL	2653	55.8	35.7	4.5	4.3	0.8	22.8	17.6	9.9	5.2	43.7	0.3	2.6	2.1	7.7
PRCNTL	41	33.1	75.3	61.7	68.1	17.9	84.1	73.7	68.7	50.8	62.1	31.7	73.7	66.7	73.9

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BBFMR	ZFMR	EXNMR	OBNMR	ISNMR	BBNMR	ZNMR	EXPMR	OBPMR	ISPMR	BBPMR	ZPMR
1970	5.3	10.3	12.8	123.7	104.3	0.5	11.2	10.4	92.4	99.8	-0.2	22.4	23.0	102.8	100.6	0.1
1971	0.3	8.6	3.2	37.2	91.9	-1.1	11.9	9.6	60.7	97.6	-0.5	12.2	12.7	70.1	95.3	-0.9
1972	11.3	7.6	20.3	283.7	121.1	2.5	7.8	3.8	38.8	95.1	-1.2	16.8	23.2	145.1	126.9	1.3
1973	12.5	11.1	18.5	165.6	110.8	1.3	13.1	11.3	86.4	98.8	-0.4	25.9	29.3	113.9	102.7	0.6
1974	21.3	11.9	15.9	133.7	107.2	0.6	16.8	20.2	119.8	105.8	0.6	27.8	35.7	132.1	109.6	1.1
1975	21.1	8.1	10.8	132.8	105.4	0.5	5.7	7.2	126.1	102.1	0.4	14.4	17.9	124.1	103.7	0.5
1976	21.4	7.5	8.8	106.5	101.3	0.1	9.7	8.8	82.6	95.5	-0.5	15.3	15.9	104.8	101.8	0.1
1977	28.7	6.8	4.7	69.4	93.7	-0.6	6.3	11.8	107.8	112.5	1.7	12.1	16.5	136.9	106.9	0.9
TOTAL	15.1	8.8	11.3	128.5	110.8	1.5	10.8	9.9	99.2	99.7	-0.1	18.4	21.1	114.9	108.9	1.3
PRCNTL	92.3	69.4	81.9	82.1	86.2	83.8	76.9	68.3	43.4	44.4	45.6	72.3	78.9	73.7	83.3	77.8

—— COUNTY:ORANGE NAME:SAN CLEMENTE GENERAL HOSPITAL CITY:SAN CLEMENTE CODE:397 HFPA:1817 ——

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1973	428	70.2	12.8	3.4	3.6	0.9	4.8	19.2	5.4	2.7	54.3	0.7	0.[illegible]	2.3	7.5
1974	539	74.6	17.1	5.1	3.1	0.7	6.7	13.4	6.3	3.3	50.6	0.2	0.7	1.1	7.2
1975	381	75.6	16.7	2.9	4.8	1.2	6.7	11.4	8.6	2.9	53.1	0.2	0.5	1.7	5.8
1976	661	76.4	18.5	1.7	3.5	1.8	11.7	15.8	4.2	4.5	49.5	3.6	0.5	0.9	5.9
1977	654	77.2	16.2	2.9	3.7	1.2	8.8	16.4	4.3	4.9	48.5	1.1	0.3	1.5	4.1
TOTAL	2873	76.4	16.5	3.4	3.7	1.2	8.8	15.1	5.7	3.8	50.9	0.6	0.6	1.5	6.0
PRCNTL	43	64.6	46.9	53.5	56.5	35.8	25.9	55.6	39.7	16.3	94.6	73.4	6.3	18.4	34.5

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BBFMR	ZFMR	EXNMR	OBNMR	ISNMR	BBNMR	ZNMR	EXPMR	OBPMR	ISPMR	BBPMR	ZPMR
1973	14.2	8.3	13.7	171.8	111.1	1.4	9.4	11.6	122.9	102.6	0.5	18.8	25.1	133.7	107.2	1.2
1974	16.4	10.4	9.3	69.5	96.2	-0.3	8.8	9.4	106.2	101.7	0.2	19.3	18.6	96.3	98.6	-0.2
1975	16.7	6.5	3.4	53.2	74.8	-1.8	8.2	8.6	105.5	101.4	0.1	13.2	12.8	91.1	97.5	-0.3
1976	19.1	4.5	1.5	33.7	67.8	-1.2	3.3	0.8	0.0	98.6	-1.5	7.8	1.5	19.5	87.3	-1.9
1977	21.1	7.3	9.2	125.0	100.2	0.6	3.9	6.2	157.6	107.0	1.0	13.6	15.3	112.4	104.3	0.5
TOTAL	17.8	7.2	7.0	97.0	96.9	-0.1	6.4	6.7	104.2	101.1	0.2	14.3	13.6	96.7	98.7	-0.3
PRCNTL	98.2	22.9	22.8	43.5	42.6	44.4	15.8	21.1	38.0	36.2	54.9	28.2	28.9	37.0	36.5	30.3

— COUNTY:ORANGE NAME:SANTA ANA-TUSTIN COMMUNITY HOSPITAL CITY:SANTA ANA CODE:398 HFPA:1813 —

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	1526	50.6	42.5	5.8	1.0	0.7	11.6	15.8	6.1	0.0	37.8	0.3	4.7	2.2	6.7
1971	1340	43.9	48.5	5.1	2.5	0.4	9.4	13.9	5.4	7.1	38.7	0.4	3.9	1.6	5.3
1972	1111	38.8	55.1	4.4	1.7	0.9	8.3	18.2	5.6	6.6	39.2	0.4	3.2	2.2	6.5
1973	917	36.0	58.4	3.8	1.7	2.1	9.6	16.0	4.1	6.1	37.6	0.3	3.9	1.5	6.3
1974	642	43.3	50.7	3.7	2.3	3.4	9.7	19.1	5.7	6.6	40.7	0.9	3.1	2.2	6.0
1975	193	42.8	49.8	6.7	1.5	7.2	15.5	18.0	8.2	3.1	42.0	0.0	2.1	0.0	0.0
1976	928	61.2	29.5	6.0	3.4	0.7	15.8	13.3	5.2	3.3	44.7	0.3	0.9	1.5	6.3
1977	1359	67.9	23.1	5.5	3.4	1.7	12.9	12.4	4.1	3.4	47.4	0.5	0.9	1.8	4.8
TOTAL	8000	49.5	43.1	5.2	2.4	1.4	11.2	16.5	5.3	5.9	40.9	0.4	3.0	1.8	6.0
PRCNTL	76	27.8	82.1	63.9	34.8	42.6	44.2	67.8	33.8	74.4	36.3	55.3	80.5	43.5	37.9

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BBFMR	ZFMR	EXNMR	OBNMR	ISNMR	BBNMR	ZNMR	EXPMR	OBPMR	ISPMR	BBPMR	ZPMR
1970	10.8	9.5	8.5	90.1	95.6	-0.4	9.3	9.9	100.1	102.8	0.3	19.8	18.3	96.4	98.2	-0.2
1971	9.2	8.5	9.7	114.5	108.6	0.5	8.3	6.8	81.7	94.8	-0.7	17.1	16.4	95.8	98.2	-0.2
1972	11.4	9.8	10.8	119.6	107.8	0.7	9.5	10.8	108.7	101.7	0.2	18.4	20.7	112.5	105.2	0.7
1973	13.2	7.3	4.4	59.5	89.2	-1.1	5.7	4.4	76.8	97.1	-0.6	13.5	8.7	64.8	90.6	-1.4
1974	12.1	7.2	10.9	158.9	114.8	1.2	6.6	6.3	95.2	99.8	-0.1	13.1	17.1	130.5	108.3	1.8
1975	15.5	14.9	5.2	34.9	84.6	-1.3	14.8	20.8	149.2	108.8	1.1	24.6	25.9	105.4	101.2	0.2
1976	16.9	8.8	6.5	74.3	88.5	-0.8	6.9	3.3	47.7	85.5	-1.5	16.1	9.8	60.7	81.7	-2.8
1977	16.5	5.8	2.9	59.1	84.9	-1.1	4.3	8.1	107.5	122.1	2.3	9.4	11.8	110.8	106.5	2.7
TOTAL	12.8	8.1	7.5	92.5	95.2	-0.7	7.5	7.7	102.8	101.1	0.2	15.7	15.1	96.4	97.6	-0.5
PRCNTL	88.3	54.3	39.7	37.6	28.6	31.7	33.6	36.3	33.5	56.7	54.2	43.8	34.5	36.1	30.6	34.8

TABLE 18. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 13 BY HOSPITAL OF BIRTH
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

— COUNTY=ORANGE NAME=SOUTH COAST MEDICAL CENTER CITY=LAGUNA BEACH-SOUTH CODE=399 HFPA=1017 —

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	961	84.6	11.9	0.8	2.6	0.5	7.2	16.6	4.5	4.9	50.7	0.6	1.1	1.9	6.9
1971	859	86.6	10.4	0.5	2.5	0.3	5.8	15.8	2.2	4.4	44.5	0.6	1.4	1.4	8.0
1972	604	78.3	17.2	0.8	3.6	0.7	6.2	12.9	4.5	6.8	47.6	0.5	1.2	0.7	7.5
1973	437	85.2	13.5	0.5	0.9	0.5	5.3	11.2	2.4	5.5	47.8	3.5	1.1	1.4	7.3
1974	465	85.0	11.6	0.4	2.8	1.3	3.7	10.9	1.3	5.8	43.9	1.1	0.7	0.9	5.7
1975	333	78.7	19.2	0.3	1.8	0.6	5.7	11.8	0.6	8.1	44.0	0.9	0.9	1.2	5.7
1976	278	90.8	6.8	0.7	2.5	0.4	0.7	5.2	0.7	8.2	30.9	1.1	1.0	2.6	5.4
1977	238	89.9	7.6	0.4	2.1	0.0	1.7	4.2	0.0	9.2	40.3	0.8	0.4	1.7	3.8
TOTAL	4185	84.5	12.5	0.6	2.4	0.6	5.2	12.5	2.7	5.7	45.9	0.7	1.1	1.5	6.7
PRCNTL	54	83.7	22.7	20.4	34.2	12.7	11.1	28.3	6.6	73.0	80.7	81.6	39.2	19.3	86.2

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	11.1	10.2	9.4	91.5	96.9	-0.3	13.4	13.7	101.0	100.6	0.1	22.0	22.9	134.0	131.8	0.2
1971	11.2	8.3	7.8	84.4	95.7	-0.4	10.8	10.6	103.0	101.3	0.2	10.8	17.5	97.2	99.1	-0.1
1972	11.7	12.8	11.6	90.8	99.8	-0.1	14.8	11.7	83.8	95.7	-0.6	24.5	23.2	94.2	97.7	-0.3
1973	12.8	9.3	6.9	74.1	98.1	-0.6	7.9	6.9	80.0	98.9	-0.2	10.1	13.7	76.8	94.8	-0.8
1974	13.1	0.0	6.6	109.3	102.4	0.2	8.2	13.3	143.8	112.9	1.5	15.6	22.8	140.7	111.4	1.4
1975	17.4	6.9	3.8	43.2	89.6	-0.9	6.2	6.0	96.0	99.6	-0.1	13.9	9.8	64.9	92.7	-1.8
1976	18.9	7.2	3.6	49.6	92.3	-0.8	10.5	10.6	183.3	100.7	0.1	16.2	14.4	89.8	97.7	-0.3
1977	18.1	6.3	0.0	0.0	86.8	-1.4	0.0	16.6	299.7	117.7	2.2	12.0	16.8	140.6	106.2	0.9
TOTAL	13.2	9.1	7.4	82.2	90.9	-1.2	10.5	11.4	107.8	103.8	0.6	18.8	18.7	99.5	99.7	-0.1
PRCNTL	81.9	73.5	30.8	28.9	15.8	17.9	82.8	62.3	62.6	72.1	66.2	75.7	65.8	43.5	42.6	43.1

——— COUNTY=ORANGE NAME=ST. JOSEPH HOSPITAL CITY=ORANGE CODE=400 HFPA=1015 ———

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	3790	84.3	10.4	2.1	2.6	0.5	5.8	14.5	3.4	6.5	43.2	0.6	1.4	1.9	5.4
1971	3079	82.6	11.7	2.2	3.5	0.2	4.8	15.1	2.5	6.4	41.3	0.6	1.7	1.7	5.8
1972	2752	81.2	12.1	1.9	4.9	0.2	4.9	14.8	3.8	5.7	42.2	0.3	1.5	2.0	5.8
1973	2739	79.9	12.7	2.8	4.6	0.2	4.6	12.9	4.5	4.7	44.8	0.4	1.2	1.6	5.8
1974	2815	77.4	14.1	3.0	5.5	0.5	5.1	10.3	3.9	4.9	44.7	0.4	1.0	1.6	5.0
1975	2352	74.7	16.4	3.1	5.7	0.3	7.0	11.4	3.6	5.1	44.6	0.6	1.1	2.2	5.7
1976	2433	76.3	16.4	1.8	5.5	0.2	6.1	11.3	2.6	6.5	43.6	1.1	0.7	1.4	5.2
1977	2815	74.5	17.1	2.7	5.0	0.4	5.2	10.3	1.7	5.3	44.2	0.7	0.5	2.0	5.0
TOTAL	23028	79.3	12.6	2.4	4.7	0.3	5.4	12.7	3.3	5.7	43.3	0.6	1.2	1.8	5.5
PRCNTL	97	71.7	36.3	40.8	67.3	2.9	11.8	31.1	11.3	71.7	59.9	76.6	41.5	42.9	19.8

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	6.9	0.1	5.5	68.7	80.3	-1.9	9.9	9.8	90.7	99.3	-0.1	17.1	15.3	89.6	92.9	-1.8
1971	7.7	7.7	5.8	76.3	86.5	-1.2	9.8	9.5	100.3	102.7	0.3	16.2	15.3	94.2	96.4	-0.3
1972	9.3	7.5	7.2	95.4	97.5	-0.2	9.6	10.1	105.7	102.8	0.4	16.6	17.2	103.6	102.2	0.3
1973	10.2	7.9	6.8	101.4	100.8	0.1	6.8	7.7	96.1	99.3	-0.2	15.9	15.7	90.5	99.1	-0.1
1974	15.5	7.1	8.5	119.9	112.9	1.8	5.8	6.1	105.9	105.9	0.3	13.2	14.6	110.6	106.8	0.8
1975	19.5	6.0	6.3	108.7	102.2	0.2	6.8	7.5	124.8	111.9	1.1	12.5	13.7	110.1	106.1	0.7
1976	21.2	6.5	7.4	112.8	107.7	0.6	5.3	4.1	77.9	98.1	-0.9	12.1	11.5	94.9	96.9	-0.3
1977	21.7	6.0	4.6	76.4	85.7	-1.8	6.5	5.7	87.6	93.1	-0.6	11.8	10.3	86.9	92.8	-0.9
TOTAL	13.4	7.2	6.6	92.8	93.5	-1.1	7.7	7.7	100.8	100.6	0.1	14.6	14.3	97.8	98.2	-0.5
PRCNTL	84.6	23.1	25.6	37.8	22.7	28.8	36.3	30.1	49.8	52.4	52.4	27.2	27.8	39.7	34.2	34.2

——— COUNTY=ORANGE NAME=ST. JUDE HOSPITAL CITY=FULLERTON CODE=401 HFPA=1011 ———

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	2817	85.9	11.9	0.4	1.8	0.3	6.5	12.2	3.2	7.2	39.4	0.5	1.7	1.1	5.6
1971	2426	85.8	12.6	0.6	1.8	0.1	4.1	13.3	3.4	7.8	38.9	0.4	1.9	2.9	5.6
1972	2270	83.3	13.7	0.4	2.6	0.5	5.4	11.7	4.3	6.5	41.5	0.6	2.8	2.4	6.2
1973	2259	83.6	13.5	0.6	2.3	0.3	5.4	12.3	2.9	6.1	42.2	0.7	1.1	1.8	5.7
1974	2373	82.9	13.7	0.8	2.6	0.3	5.9	11.3	3.8	5.6	44.0	0.6	1.5	2.1	5.6
1975	2337	81.8	15.5	0.9	2.6	0.3	6.1	12.8	3.9	5.1	46.5	0.7	1.6	1.7	4.6
1976	2382	79.6	16.1	1.3	3.5	0.2	10.9	9.5	4.8	5.3	45.2	0.6	1.2	2.2	5.0
1977	2152	78.0	16.8	0.7	4.5	0.4	7.2	10.5	2.9	4.7	43.8	0.6	0.6	1.0	3.7
TOTAL	18956	82.6	14.8	0.7	2.7	0.3	6.4	11.7	3.5	6.0	42.5	0.6	1.5	1.9	5.4
PRCNTL	96	79.6	30.3	22.8	41.3	2.3	16.6	19.3	15.8	75.3	58.3	76.2	51.7	52.6	16.3

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BSFMR	ZFMR	EXNMR	OBNMR	ISNMR	BSNMR	ZNMR	EXPMR	OBPMR	ISPMR	BSPMR	ZPMR
1970	4.5	8.9	9.2	103.7	102.2	0.2	10.4	10.8	96.3	98.8	-0.3	19.8	13.2	100.4	100.5	0.1
1971	4.4	8.2	7.4	98.4	94.9	-0.5	9.8	9.6	97.1	98.7	-0.2	18.0	16.9	93.8	96.2	-0.5
1972	5.8	8.8	11.9	135.2	119.3	1.8	7.9	6.7	84.7	94.4	-0.8	10.1	18.5	102.8	101.3	0.2
1973	6.4	8.5	8.9	104.2	102.2	0.2	9.3	11.2	128.6	109.2	1.2	17.2	19.9	115.6	109.3	1.3
1974	9.3	8.3	9.3	111.9	107.9	0.6	7.6	11.5	131.4	129.1	2.7	16.3	20.6	128.9	120.8	2.3
1975	9.8	6.8	6.8	99.8	99.5	-0.8	6.9	6.9	99.2	99.6	-0.8	12.9	12.8	99.9	99.9	-0.8
1976	12.8	6.8	12.9	191.8	154.3	3.9	6.2	5.7	91.4	95.6	-0.4	13.8	10.5	142.4	128.2	2.9
1977	14.1	5.6	5.1	90.9	98.2	-0.3	5.3	4.7	88.9	98.3	-0.4	10.3	9.8	94.4	97.1	-0.3
TOTAL	8.1	7.7	9.9	115.3	112.2	2.2	8.8	8.4	104.2	103.2	0.6	15.7	17.1	109.1	107.7	2.3
PRCNTL	36.5	48.6	60.1	78.3	90.5	89.3	46.8	45.4	58.3	60.6	64.8	44.9	56.2	66.2	86.2	87.5

TABLE 18. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 13 BY HOSPITAL OF BIRTH
SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

——— COUNTY:ORANGE NAME:STANTON COMMUNITY HOSPITAL CITY:STANTON CODE:482 HFPA:1012 ———

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	260	88.5	11.1	0.0	0.4	1.5	12.2	14.1	9.2	3.8	45.0	0.4	0.8	0.0	4.6
1971	180	83.0	15.9	0.0	1.1	0.5	6.2	17.0	7.1	6.0	41.2	0.0	3.0	1.1	9.9
1972	128	76.6	23.4	0.0	0.0	10.9	13.4	13.0	12.5	1.6	46.1	0.0	0.0	1.6	7.0
1973	103	80.6	16.5	1.0	1.9	3.9	10.9	13.1	6.8	2.9	40.8	0.0	1.0	1.9	11.7
1974	104	74.0	23.1	0.0	2.9	4.8	18.4	23.6	8.7	4.8	47.1	0.0	2.9	1.9	8.7
1975	43	62.8	37.2	0.0	0.0	2.3	11.6	19.0	9.3	2.3	51.2	0.0	0.0	0.0	4.7
1976	3	100.0	0.0	0.0	0.0	0.0	0.0	.	0.0	0.0	100.0	0.0	0.0	66.7	33.3
1977	2	50.0	50.0	0.0	0.0	50.0	0.0	0.0	50.0	0.0	50.0	0.0	0.0	0.0	0.0
TOTAL	823	81.3	17.7	0.1	1.0	3.6	11.6	16.0	8.9	3.9	44.9	0.1	1.6	1.2	7.8
PRCNTL	18	75.7	50.0	4.5	9.1	80.3	46.3	64.4	75.7	19.7	72.6	14.1	56.8	0.6	74.0

COHORT	CSEC	EXFMR	OBFMR	ISFMR	SBFMR	ZFMR	EXNMR	OBNMR	ISNMR	SBNMR	ZNMR	EXPMR	OBPMR	ISPMR	SBPMR	ZPMR
1970	14.1	5.6	0.0	0.0	93.3	-1.2	5.9	15.4	259.2	106.0	2.0	11.3	15.4	125.0	102.4	0.6
1971	22.0	7.3	22.2	204.0	112.5	2.4	7.7	5.7	73.5	99.1	-0.3	15.1	27.8	183.0	105.2	1.4
1972	15.6	6.6	7.8	119.1	100.6	0.2	6.3	7.9	124.3	100.5	0.2	13.0	13.6	120.0	100.0	0.3
1973	23.3	19.0	19.4	182.4	100.3	0.0	21.3	19.0	93.0	99.6	-0.1	30.6	30.0	100.7	100.1	0.0
1974	15.4	14.7	9.6	65.5	95.3	-0.5	22.2	29.1	131.2	107.2	6.0	37.0	30.5	101.6	100.5	0.1
1975	14.0	3.0	0.0	0.0	98.7	-0.4	2.0	0.0	0.0	99.4	-0.4	6.7	0.0	0.0	99.0	-0.5
1976	0.0	0.9	0.0	0.0	99.8	-0.2	4.4	0.0	0.0	99.9	-0.1	13.3	0.0	0.0	99.9	-0.2
1977	0.0	5.2	0.0	0.0	99.9	-0.1	2.6	0.0	0.0	100.0	-0.1	7.7	0.0	0.0	99.9	-0.1
TOTAL	17.3	8.9	9.7	109.7	101.5	0.3	10.2	13.5	132.0	104.0	1.2	18.9	23.1	122.0	104.6	1.1
PRCNTL	97.5	70.1	60.7	64.2	57.1	56.5	70.9	91.6	86.6	76.0	77.0	70.2	84.4	82.3	71.9	71.2

——— COUNTY:ORANGE NAME:UC IRVINE MEDICAL CENTER CITY:ORANGE CODE:483 HFPA:1015 ———

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	2257	54.1	40.0	2.3	2.0	0.5	15.0	25.2	9.0	5.4	37.9	0.1	5.4	1.7	10.4
1971	2322	49.0	44.5	3.3	2.4	0.1	17.4	24.5	11.6	5.5	41.7	0.1	4.3	1.7	8.9
1972	2421	46.1	46.9	4.0	2.9	7.1	19.1	25.1	11.1	4.5	40.0	0.2	4.3	2.5	9.2
1973	2233	39.3	55.5	3.0	2.2	0.4	19.7	23.1	10.7	5.9	40.9	0.4	5.0	2.2	9.1
1974	2545	36.2	58.6	3.2	2.0	9.7	22.1	23.9	9.5	6.1	41.1	0.2	5.5	1.5	7.5
1975	2400	31.7	61.6	3.5	2.9	12.2	24.8	23.3	9.9	6.0	39.6	0.4	5.5	1.5	7.1
1976	2897	31.2	62.2	2.8	3.8	14.5	24.4	23.5	8.5	5.5	40.5	0.2	4.7	1.7	8.0
1977	3199	28.8	62.7	2.7	5.0	17.5	27.6	24.3	8.7	5.5	40.6	0.3	5.1	2.1	9.1
TOTAL	20362	38.8	54.8	3.1	3.2	11.1	21.8	24.1	9.9	5.5	40.4	0.2	5.0	1.9	8.7
PRCNTL	96	17.2	98.5	91.2	91.2	90.4	82.1	97.5	83.4	67.3	31.1	28.1	95.0	46.9	85.9

COHORT	CSEC	EXFMR	OBFMR	ISFMR	SBFMR	ZFMR	EXNMR	OBNMR	ISNMR	SBNMR	ZNMR	EXPMR	OBPMR	ISPMR	SBPMR	ZPMR
1970	3.7	12.6	17.3	137.0	122.0	2.2	11.3	9.0	79.5	91.1	-1.2	26.0	26.1	100.7	100.5	0.1
1971	6.1	13.7	11.6	84.7	89.9	-1.0	15.2	16.1	105.9	103.6	0.5	29.3	27.6	94.1	98.5	-0.7
1972	8.0	11.4	9.1	79.7	87.4	-1.2	11.9	11.7	90.5	99.2	-0.1	23.3	28.7	88.7	92.5	-1.1
1973	10.1	11.3	9.6	79.0	87.6	-1.2	12.9	13.1	101.2	100.6	0.1	23.0	21.9	95.4	97.0	-0.4
1974	11.2	12.3	13.0	112.1	109.2	0.8	12.4	12.4	100.0	100.0	-0.0	23.1	25.9	112.0	109.5	1.2
1975	12.1	9.7	8.4	87.3	91.1	-0.7	7.5	6.9	91.9	95.3	-0.4	16.0	15.3	91.1	93.0	-0.7
1976	13.0	12.0	8.3	69.1	76.1	-2.0	11.5	10.1	87.7	91.2	-0.9	22.0	18.3	80.4	84.3	-2.1
1977	13.7	11.1	10.0	90.0	92.2	-0.7	10.9	8.2	75.2	82.3	-1.8	21.0	18.1	86.1	89.1	-1.4
TOTAL	10.3	11.7	10.8	92.1	93.2	-1.3	11.6	10.8	92.6	93.8	-1.4	23.0	21.5	93.3	94.0	-1.9
PRCNTL	37.1	92.5	70.7	37.4	21.3	15.2	89.1	77.6	32.7	16.0	13.2	91.2	88.5	31.1	15.9	18.4

——— COUNTY:ORANGE NAME:W. ANAHEIM COMMUNITY HOSPITAL CITY:ANAHEIM CODE:484 HFPA:1012 ———

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	OPARA1	PARA6	MULT	LOBW
1970	844	86.9	10.5	0.2	2.4	1.5	7.9	13.6	6.4	4.7	43.4	0.4	2.0	3.1	6.9
1971	884	81.7	13.4	0.1	4.8	0.7	7.6	15.3	7.1	5.1	46.5	0.1	1.5	2.7	8.1
1972	947	79.3	14.8	1.0	5.0	0.6	12.5	13.0	8.1	4.1	50.4	0.4	1.0	2.5	6.5
1973	989	77.9	16.4	0.5	5.2	0.6	12.3	14.1	8.0	3.9	47.4	0.2	1.2	0.9	4.0
1974	895	76.6	14.3	0.7	8.5	0.0	8.5	12.2	5.0	4.0	46.1	0.2	0.7	1.5	7.6
1975	773	74.4	15.8	0.5	9.3	1.7	6.0	11.5	4.5	2.6	43.6	0.3	1.0	1.6	6.0
1976	661	73.4	17.2	1.2	8.2	1.1	7.8	12.6	3.8	3.5	44.0	0.3	0.6	2.7	5.6
1977	779	72.3	18.1	0.5	9.1	0.5	5.8	11.1	4.0	4.5	48.7	0.3	1.0	3.1	5.1
TOTAL	6622	78.0	15.0	0.6	6.4	0.9	8.7	13.1	6.1	4.1	46.1	0.3	1.1	2.2	6.4
PRCNTL	69	67.8	40.0	20.0	78.9	22.7	20.0	35.0	44.7	24.0	82.3	32.7	39.7	81.2	40.5

COHORT	CSEC	EXFMR	OBFMR	ISFMR	SBFMR	ZFMR	EXNMR	OBNMR	ISNMR	SBNMR	ZNMR	EXPMR	OBPMR	ISPMR	SBPMR	ZPMR
1970	11.5	9.2	13.0	145.6	112.5	1.4	10.0	9.6	96.0	99.1	-0.1	10.7	22.5	120.2	107.0	1.0
1971	13.2	7.5	5.0	66.6	91.8	-0.9	8.3	10.8	121.1	103.6	0.6	16.0	14.9	93.3	98.1	-0.3
1972	15.5	7.6	5.3	69.7	91.5	-0.9	9.4	8.5	90.2	97.7	-0.4	16.5	13.7	83.1	94.3	-0.8
1973	20.0	5.7	2.2	37.9	86.0	-1.5	5.9	8.6	145.4	106.3	1.2	11.2	10.0	96.2	99.2	-0.1
1974	10.0	7.9	6.7	88.4	94.4	-0.4	7.4	9.0	121.9	106.3	0.6	15.1	15.6	103.0	101.4	0.2
1975	15.4	6.8	7.0	114.6	104.0	0.4	7.7	5.2	67.7	98.7	-0.9	14.7	12.9	88.1	95.5	-0.5
1976	19.2	7.9	4.5	57.4	85.5	-1.1	8.6	15.2	177.3	124.5	2.4	16.5	19.7	119.5	108.0	0.9
1977	20.4	5.7	5.1	90.7	97.4	-0.2	4.7	2.6	54.9	91.7	-1.0	11.0	7.7	70.3	91.1	-1.0
TOTAL	16.7	7.2	6.2	85.6	92.0	-1.1	7.7	8.5	109.6	104.0	0.0	14.9	14.6	90.0	90.0	-0.2
PRCNTL	96.1	25.2	20.9	25.2	17.2	20.9	30.5	47.0	65.0	75.7	69.6	32.0	29.0	40.1	37.0	29.0

TABLE 18. 1970-1977 CALIFORNIA VITAL RECORD DATA FOR HSA 13 BY HOSPITAL OF BIRTH

SOURCE: MATERNAL AND CHILD HEALTH DATA BASE AT THE UNIVERSITY OF CALIFORNIA, SANTA BARBARA

--- COUNTY=ORANGE NAME=WESTMINSTER COMMUNITY HOSPITAL CITY=WESTMINSTER CODE=485 HFPA=1014 ---

COHORT	BIRTH	WHITE	SPAN	BLACK	OTHER	NOPRE	OUTWED	SHORT	TEEN	OLDER	PARA1	2PARA1	PARA6	MULT	LOBW
1970	982	87.9	8.5	0.1	3.6	0.2	7.0	13.4	7.7	5.2	40.9	0.4	1.6	1.0	7.5
1971	987	85.2	12.1	0.3	2.4	0.1	8.7	15.1	7.8	5.8	41.9	0.1	2.1	1.3	7.6
1972	756	85.1	11.6	0.3	3.0	0.1	8.9	12.5	7.1	4.5	43.0	0.1	1.1	1.1	5.4
1973	476	80.3	15.8	0.2	3.6	0.2	7.9	11.8	8.6	5.3	46.4	0.4	1.9	1.7	6.7
1974	486	80.5	15.4	0.4	3.7	0.0	15.9	15.9	8.8	3.9	44.6	0.0	0.6	1.0	6.4
1975	853	71.3	18.7	5.7	4.2	1.2	23.2	13.5	7.3	3.4	41.0	0.6	1.1	2.1	7.7
1976	1219	62.2	24.6	7.6	5.6	1.7	29.7	12.3	7.9	2.9	42.0	0.6	1.6	2.0	8.3
1977	1129	60.3	24.6	8.8	6.3	2.5	26.3	14.9	6.0	3.9	38.8	0.3	0.8	1.4	6.5
TOTAL	6888	74.9	17.2	3.7	4.3	1.0	17.4	13.7	7.5	4.2	41.9	0.2	1.4	1.6	7.2
PRCNTL	78	68.5	49.4	56.5	63.3	25.4	72.8	43.5	64.6	20.6	48.4	26.5	47.6	25.4	68.7

COHORT	CSEC	EXFMR	OBFMR	ISFMR	BBFMR	ZFMR	EXNMR	OBNMR	ISNMR	BBNMR	ZNMR	EXPMR	OBPMR	ISPMR	BBPMR	ZPMR
1970	4.2	8.7	18.2	117.3	186.5	0.5	10.0	9.3	92.7	98.2	-0.3	10.6	19.3	103.0	101.4	0.2
1971	4.9	9.8	6.6	67.6	89.1	-1.1	11.5	11.1	96.7	99.1	-0.1	21.5	17.6	82.1	92.6	-1.8
1972	7.9	5.7	2.6	46.5	90.4	-1.1	6.4	5.3	83.5	90.8	-0.4	11.7	7.9	67.6	93.8	-1.1
1973	10.7	6.9	12.6	101.6	111.0	1.5	7.0	8.5	121.0	101.0	0.4	13.9	21.0	131.2	107.7	1.4
1974	14.2	7.2	8.2	114.4	103.4	0.3	6.2	2.1	33.7	91.0	-1.2	13.7	10.3	73.1	94.3	-0.7
1975	17.9	7.2	5.9	88.9	93.2	-0.5	7.3	4.7	64.0	98.2	-1.0	14.4	10.6	73.1	98.1	-1.1
1976	17.6	8.9	4.1	45.9	72.9	-1.9	11.1	13.2	118.3	109.4	0.9	19.0	17.2	98.5	94.6	-0.6
1977	18.5	8.6	8.9	103.2	101.6	0.1	8.7	8.9	103.1	101.3	0.1	16.9	17.7	104.9	102.6	0.3
TOTAL	12.4	8.1	7.1	86.9	92.3	-1.8	9.3	8.6	95.9	97.7	-0.4	16.0	15.6	92.6	95.1	-1.0
PRCNTL	77.8	54.2	33.1	27.4	19.8	21.3	63.7	49.2	36.0	32.8	34.5	58.7	39.8	29.5	28.2	22.4

Cancer: Twisting the Statistics About Its Causes

Chemical Industries Try to Shift the Blame From Their Own Products to Workers' Life Styles

By SAMUEL EPSTEIN

With cancer, as with much else that we fear and cannot fully explain, we develop popular mythologies to explain what science has not. Unfortunately, some are dangerously misleading, and may be preventing us from avoiding unnecessary cancers.

One such current myth, propagated through the unlikely and unwilling partnership of holistic health advocates and the nation's chemical industries, holds that the causes of virtually all cancers are rooted in life styles. The implication is that if you contract cancer it is essentially your fault.

As with all myths, this one contains a germ of truth. Smoking, for example, is clearly a life-style choice that contributes heavily to our high rate of lung cancers.

But while holistic health practitioners stress the positive aspects of the importance of life style—their point is that we are at least to some extent responsible for our own health—U.S. chemical industries are making deliberate use of the argument in an attempt to escape responsibility for the cancers caused by their own products.

Fearing increased federal regulation, industry-sponsored physicians and scientists have manipulated statistics, withheld critical information and, in several cases, misrepresented data in studies produced for industry lobbying efforts. One recent report, produced by the American Industrial Health Council—an organization created by the chemical industry to fight regulation of carcinogens in the workplace—claims that cancer is actually on the decline, that all recent increases in cancer mortality rates are due to smoking and that industrial chemicals are responsible for no more than 5% of all cancers in the United States.

Examination of recent evidence, however, shows that, although life-style factors are important contributors to cancer mortality, the role of occupational and environmental carcinogens has been grossly underrated. Moreover, industry and industry-funded consultants are greatly exaggerating the role of even such clearly dangerous life-style factors as smoking in their attempt to divert public attention from the occupational causes of lung and other cancers.

Thus, the mining and textile industries have for many years pointed to smoking as the primary culprit in the high rates of black- and brown-lung cases, respectively, among their work forces, even though more likely causes are coal dust and cotton fibers.

Contrary to industry claims that all increases in cancer mortality have been due to smoking, the lung-cancer rates for non-smokers approximately doubled between 1958 and 1980, and have continued to rise. Of the approximately 100,000 annual lung-cancer deaths in the United States today, about 20% involve non-smokers.

Further challenges to the dominant role ascribed to smoking are provided by studies of specific occupational groups. For example, lung-cancer rates among American Indian uranium miners, Swedish zinc-lead miners and others exposed to a wide range of industrial carcinogens are about as high in non-smokers as smokers.

Certain ethnic groups have higher risks of lung cancer, not because they smoke more but because they are concentrated in certain types of occupations. Topside coke-oven workers, for example, with five or more years on the job, have a lung-cancer rate up to 10 times that of steel workers in general. Roughly 75% of the topside workers are non-white, whereas only about 12% of the non-topside workers are non-white.

The relative risks of lung cancer for smokers versus non-smokers have been grossly overestimated because of a failure to consider the effect of non-voluntary exposures to carcinogens in the environment. Variations in smoking, for example, do not account for the significant excess of lung cancers in both men and women living in communities adjacent to petrochemical and other industrial plants. A large number of studies have found sharp increases in lung cancer in areas with heavy air pollution.

Evidence continues to grow that involuntary exposures may have a much larger role in causing other types of cancer as well.

During the seven years between 1969 and 1976, U.S. cancer mortality climbed more than 5%, a rate of increase similar to that of the preceding 35 years. The overall probability of a person born today getting cancer by age 85 is calculated to be about 27%, in contrast to 1950, when it was only 19%.

It is not mere coincidence that increases in cancer mortality follow the growth of our chemical industries. Recent cancer rates reflect exposures to carcinogens 20 to 30 years ago. The production of synthetic organic chemicals, which include many known and suspected carcinogens, was only about 1 billion pounds in 1935, but rose to 30 billion by 1950 and 300 billion by 1976.

The five states with the highest cancer rates are found in the Northeast, where the nation's heavy industry is located. By contrast, the states with the lowest cancer rates are in predominantly rural Western and Southern states, where there is relatively little industry.

Higher production levels of industrial chemicals have increased the exposures not only of industrial workers, but of the general public as well. Prior to the passage of the 1976 Toxic Substances Act, which the chemical industries stalled for years, there were no requirements for testing chemicals before use. Thus, the ovewhelming majority of the thousands of chemicals now in use have never even been tested for carcinogenic effects. To make matters worse, the chemical industries refuse to disclose the identity of many chemicals to which workers are exposed, claiming that the need for trade secrecy prevents such disclosure.

It is clear that industry consultants have no basis at all, other than self-serving and wishful thinking, for their "guess" that the industry's products are responsible for only 5% of the cancers contracted each year.

A recent study by a committee of internationally recognized experts from three federal agencies arrived at a completely different conclusion. This study, based on a review of more than 5,000 workplaces, estimates that up to 38% of total cancer mortality over the next 30 years will be associated with past exposure to asbestos and five other major industrial carcinogens. This estimate, it should be noted, does not even include the effects of radiation and a very wide range of other occupational carcinogens.

Many cancers are preventable—simply through removal or control of the cancer-causing agent. This will require not only individuals' dropping certain habits such as smoking, but also greater regulation of carcinogens in the environment and the workplace. The chemical industry's efforts to escape regulation by clouding the issues so far have been quite successful. But they also have cost many lives, and will claim still more until the industry's self-serving arguments are exposed for what they are.

Samuel Epstein is a professor of occupational and environmental medicine at the University of Illinois, Chicago, and the author of "The Politics of Cancer." He wrote this article for Pacific News Service.

Mr. **Scheuer**. We thank you very much for your extremely thoughtful and helpful testimony. We will be in touch with you informally.

We are now going to hear from E. R. Gabrielli, editor-in-chief of the Journal of Clinical Computing, author of three books, four monographs and more than 100 scientific papers. Editor-in-Chief: Journal of Clinical Computing and Editor: Journal of Medical Systems.

We are running late. Your prepared paper will be printed in the hearing so I suggest that you talk to us informally for 8 or 10 minutes and I am sure we will have some questions for you. And please react if you would to anything that has been said here this morning as well as the questions that we directed to you.

STATEMENT OF E. R. GABRIELLI, M.D., EDITOR-IN-CHIEF, JOURNAL OF CLINICAL COMPUTING

Dr. **Gabrielli**. Thank you very much, sir. I have prepared testimony, ready for printing, but I would like to comment extemporaneously on what I learned this morning which was to me extremely educational. As a first comment, I should emphasize that using computers is as new to medicine as using X-rays or microscopes once were. It is a milestone in the history of medicine and calls for a totally new attitude. When we switched from automobiles to airplanes we had to build airports. We have not built our airports in computers and medicine. The first testimony this morning convinced me personally that using the old approaches is really just extending the Gutenberg culture into the new era. We should not ask the major agencies to go out and collect data for millions of dollars when the data are already there. To make a diagnosis, the cost is approximately $800 per patient in the hospital. This is thrown away somebody else comes and collects data separately. The doctor knows the patient best. His diagnosis is written down as accurately he can make it. It is most unfortunate that in our system these data are generally coded by very limited trained coding clerk in the hospitals, distorting the codes and the accuracy of the information.

The National Institute of Medicine proved only 60 percent of the coded data are correct. We have a 40-percent error rate right there. The coding system in the United States is so bad sir, that the medical truth is often totally ignored. The coding system works only for the statistician. For instance it cannot separate "possible carcinoma of the colon" from "carcinoma of the colon." The code is the same, despite the significant difference in meaning. Our basic data coding is so bad we cannot really create an accurate information system in this country until we insist on accuracy at the level of the physician and his record.

This morning there was a great deal of discussion about what technology can do, but there was a tendency to try to extend the old system and build upon the old rules instead of starting anew.

I think the concept of a national information system calls for terminals in all doctors' offices. This demands about 500,000 terminals in the country and a network to pick up the data from the doctors' offices. Those offices are where the real action is, not in the hospital. The hospital uses up the most money, but the doctor's office is where all the long-term decisions are made. The doctor has to be supported at the bedside and in his office practice by a computer system so that we can both improve the quality of medicine and reduce the cost of medicine. Computerization has this potential, but so far computers have been used mostly for trivial purposes such as billing. I think the challenge of the 1980's is to exploit this technology which has been used very successfully in businesses and industry but not at all in medicine.

Probably the main reason for this is the attitude change that is required to fit into an electronic environment when practicing medicine. As you suggested very accurately, Mr. Scheuer, the doctor's self-image has to change to accept the information flow from the computer as an assistance. The last profession still working entirely from memory is medicine. The architects do not, the teachers do not. The lawyers do not. They all use library time to update themselves before making decisions. Yet you expect the physician to instantly know and remember everything when the bedside decision is to be made. I think that it was a tragedy of the 1970's that we fragmented medicine into specialties, and even super-specialties. We ended up with a fragmented, very expensive medical system which can and must be reversed into a cohesive coordinated system by the proper use of high technology.

May I answer several of your questions of this morning concerning how to do it. Being one of those who currently builds such a medical network, I do not feel old routine solutions are very suitable for supporting a new system. By giving the development of such a system to any of the agencies which carried the ball for the last 15 years, we may elicit efforts to justify past decisions. I think a totally new approach is needed. I call for a completely new, bold, imaginative, approach where private sector and the Government should form a partnership, remove all commitments of the past, and use the best brains of the country. Imagination is where the shortage is, not technology. Technology is here. We know how to do it. The big problem is the human, to organize the physicians, the hospitals, and the health care system to accept the new design. I believe psychiatrists should be hired to think about the man-machine system, to work on the interface between man and his machines. It is entirely different than it was in the "Gutenberg system" where you memorized in the library and you recalled what you knew when you needed it. Here you are using information directly out of the computer like you use the telephone directory for the appropriate telephone number whenever you need that number. Just using technocrats would be a terrible mistake, the same as it would be a mistake to use bureaucracy to force this new system upon us. We have made many major mistakes in the 1970's installing and forcing data centers upon the medical community which were foreign bodies, not accepted by the medical community or the patient community since enticing carrots were totally absent. They were self-serving data systems. In spite of this, they have undergone uncontrolled, cancerous growth. We have to rethink everything. We have to start a new world of computer-supported medicine and for that totally new rules have to be written. This is really the essence of my suggestions this morning. It is totally possible today to record what medicine knows, where the front lines of medical knowledge are. However, we do not have a good information delivery system to physicians. Television is the fastest information flow today. We know what the President said and what happened in Gdansk. The ticker machines keep investors just minutes behind stock exchange prices. Medicine is about 10 or 15 years behind its data. This all increases cost, reduces the quality of care and eventually hurts the patient who is really at the center of this whole problem.

[The prepared statement of Dr. Gabrieli follows:]

JOURNAL OF CLINICAL COMPUTING

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A COORDINATED HEALTH INFORMATION SYSTEM:

NEEDS, ISSUES, AND PLANNING

(Joint Hearing by the Subcommittee on Science, Research and Technology and the Subcommittee on Natural Resources, Agricultural Research and Environment, June 2, 1981)

Testimony of

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PROBLEM OF INFORMATION HANDLING IN MEDICINE

Only two or three decades ago, U.S. medicine was our national pride, the much envied model for the entire world. Today, the quality of our patient care is frequently challenged. The fact is, our patient care is still excellent, but perhaps not always in line with the newest research reports. The growing problem is medicine's inability to keep up with all the new information published in all the scientific journals.

Some recent studies quantified the pace of progress in biomedicine. Certain representative clinical conditions were chosen, and the dates of the major discoveries in these chosen areas, leading to our current level of knowledge, were tabulated chronologically. From these data documenting the rate of progress in specific diseases, an average rate of progress could be calculated.

This study showed that, at least for the last 50 years, the average rate of knowledge growth in medicine was 5 per cent per year, compounded annually. This now rapidly accelerating pace of knowledge growth has created some grave problems for U.S. medicine.

In the early 1930s, after finishing medical school, the young physician was adequately trained in all aspects of clinical medicine; by the 1940s, the amount of new clinical information approached the capacity of the human memory. It was necessary to break up clinical medicine into specialty areas such as surgery, neurology, internal medicine, obstetrics, pediatrics and psychiatry. Table I shows the impact of this growing knowledge upon medical education in the U.S.

Year	Annual Growth of Published Knowledge*	Training Program	Duration of Training in Years
1930	5	Medical School	4
1940	7	Medical School followed by Specialization	5-6
1950	10	Medical School followed by Residency	6-10
1960	21	Medical School followed by Residency and Subspecialty	6-12
1970	35	Medical School followed by Residency and Superspecialty	6-14

TABLE I: Development of medical education in the U.S. during the last 50 years. *Annual Growth of Published Knowledge: Arbitrary units of clinical knowledge with the fixed reference point at 1930 as total clinical knowledge = 100 units.

The first response of medicine to the rapid growth was specialization. This trend has reduced the field of expertise, and increased the length of training.

In the 1950s, it became necessary to further subdivide the initial specialty areas. For example, within the specialty of internal medicine, subspecialties have emerged such as cardiology, hematology, gastroenterology, rheumatology, allergy and many others. This trend of fragmentation continued throughout the 1970s, and today the number of specialties is well in excess of 100.

II. FRAGMENTED PATIENT CARE

As physicians were forced to divide the field into smaller and smaller segments, it became increasingly difficult to provide cohesive and coordinated care to a growing portion of clinical cases. A patient with diabetes mellitus associated with some common complications required the help of a gamut of specialists ranging from a cardiologist for coronary heart disease, to a neurologist for neuropathy to an opthalmologist for cataract. As a result, medical care became more and more expensive, and, for many patients this meant a bewildering chain of referrals, often with conflicting therapeutic recommendations.

III. KNOWLEDGE DEFICIT

Despite the rapid division of clinical medicine into smaller and smaller specialty areas, coping with new knowledge had become increasingly difficult during the 1960s. Actually, a gap has developed between what is known to researchers and the care rendered to the patients. This difference between the frontlines of clinical knowledge and actual clinical performance is the medical knowledge deficit. The leaders of U.S. medicine and medical educators became alarmed by the rapid growth of this knowledge deficit. Their instant answer to this was forced learning in order to keep the practitioners current. The American College of Physicians summarizes new information to help the busy clinician. The American Medical Association imposes mandatory continuing education on all practitioners. Periodic reexamination and re-licensing are some other tools for forced continuing education. To somewhat quantify this problem, Table II shows the growing need for learning in medicine.

UPDATING TIME	YEAR
340 hours	1940
850 hours	1950
1500 hours	1960
2770 hours	1970

TABLE II: Updating time is the total number of hours of reading required to keep up with new knowledge published in one year. Note: in 1970, a physician could remain current by reading some 53 hours per week. The exact values for 1980 are not available, but are estimated at around 5800 hours.

IV. SHIFT IN SELECTION OF PHYSICIANS

Medicine is traditionally a humanitarian scientific art. The desire to help the sick was always a primary motivation for the applicants to medical schools. During the last 2 to 3 decades, the criteria for admission to medical schools have been shifting. Today, the single overriding criterion is the grade average in college courses, particularly in organic chemistry, biology and physics. This has resulted in a corresponding shift in the nature of the applicants to medical schools. A new breed of applicant has emerged; those who could memorize organic chemistry with ease are now the typical successful applicants. This trend may affect U.S. medicine adversely for many years. Selection of medical students for their memorizing ability, often at the expense of compassion, social consciousness and ability to make rational judgements may prove to be a high price to pay in the future for an efficient knowledge handling capability today.

V. INFORMATION HANDLING IN MEDICINE IS UNIQUE

In all other professions such as architecture, physics or the law, the education goal is to build a corpus of memorized knowledge which can serve as an adequate data base for efficiently locating specific current information and also as a data base for excercising professional judgement. Today, medicine is the only profession which still uses memorized knowledge as the sole source for clinical decision making.

The physician is expected to memorize all the information on all the clinical conditions, and to "know," when needed, all the pertinent facts for the best diagnosis and therapy of any disease, at least within the domain of his specialty.

Another unique aspect of medicine is the method of information dissemination. Progress in medicine follows a well-established 4-phase cycle: (1) a researcher develops a theory and collects proof to substantiate the theory; (2) the proven theory is published; (3) experts evaluate the research report and include new findings in the next version of a textbook or monograph; (4) practicing physicians read-memorize-recall new knowledge at the bedside. This information cycle is 4-6 years long, far too slow compared to the actual rate of progress in the research laboratory.

Convincing clinical evidence requires a large body of empirical patient data. Collection of sufficient numbers of clinical cases to prove the value of a drug, a diet, or a new surgical procedure may take 5 to ten years, far too slow in our technological culture with agricultural manipulations, and with air and water pollution. Our technological inventiveness has outstripped our ability to establish health hazards before widespread use of new chemicals or manufacturing procedures. Information handling in memory-based clinical medicine is now in grave difficulties.

While the problems of biomedical knowledge handling are still increasing, there is a viable alternative, the thesis of my testimony.

VI. CONCEPT OF A COMPUTER-BASED NATIONAL MEDICAL INFORMATION SYSTEM

Today, information systems using computerized data banks are numerous in business, science and technology. A computer-based information system could alter the traditional memorizing of all medical knowledge. The computer could retrieve the trival facts needed for a clinical decision such as the success rate for particular operations or the list of ranked antibiotics for the treatment of a particular microbial infection. This concept leads to a man-machine partnership where the human memory is assisted by the machine. Computerizable information is retrieved when needed. This would promptly reduce the pressure of memorizing all new drugs, diseases, methods. Instead, the electronic memory would be kept current by removing obsolete data and by adding all the new information.

VII. OPERATIONAL OUTLINE OF A NATIONAL MEDICAL INFORMATION SYSTEM

1) One main component of a medical information system is the terminal station. Several hundred thousand terminal stations will be required, to be readily available to authorized users throughout the entire health care industry. Terminal stations will be needed in hospitals, clinics, medical offices, nursing homes, in order to enter medical records and to retrieve needed information. The actual "hardware" serving as a terminal station will range from the simplest "dumb" terminal (typewriter or cathode ray tube with keyboard) to a full microcomputer-disk-printer configuration. The size of the hardware should reflect the frequency of usage of the medical information system.

2) Each medically cohesive geographic area should have a regional data center. These centers should provide the technical support for the region's terminal stations, and they should also be responsible for the adequacy of the data security system, an essential component of a national medical information system. Furthermore, these regional medical data centers should become an important new information resource for the area's health care delivery system.

3) The third part of the medical information network, besides the terminal stations and the regional data centers, is the national medical master computer, the brain of the entire system. The master computer would maintain three types of data banks:

a) statistical summaries of case histories combined as clinical experience, kept current by rebuilding it on a daily basis;

b) knowledge bank containing the current electronic textbooks and monographs in an instantly retrievable form;

c) summaries of recent research findings--the newest concepts and studies of apparent importance, awaiting further substantiation.

The task of the national medical master computer is to organize new clinical data and knowledge and keep it in a readily retrievable form, able to answer any medical questions submitted in natural language (English).

VIII. SOME FUNCTIONS OF A MEDICAL INFORMATION SYSTEM

Perhaps the most convenient way to describe the major functions of a national medical information system is to list them according to the benefits accruing to the different types of users:

a) Physicians

Practicing physicians will use terminals in the hospitals, clinics, nursing homes, and in private offices; many will keep a terminal at home. The medical records and various diagnostic reports will be entered at the terminals by trained clerks, so that all patient records will be electronically stored by the medical information system.

A physician will routinely use the terminal station for the following purposes:

1) to retrieve a patient's record;
2) to analyze his own practice, his own diagnostic accuracy and his own success treating certain disease categories;
3) to compare his clinical results with the results of others treating the same clinical conditions;
4) to consult the pooled clinical experience bank before a clinical decision so that the decision can be guided by the pooled experience in other similar cases;
5) to consult the information system by asking for the pertinent passages of electronically stored textbooks and monographs;
6) to consult the "bank of recent advances in medicine" for pertinent research findings.

b) Patients

Patients will be the greatest beneficiaries of a medical information system. Instant availability of a blood group, or a recent electrocardiogram will be lifesaving in certain emergencies. Reliable and comprehensive longitudinal health records will be of great value to avoid potentially fatal errors, such as administering penicillin to a patient with penicillin sensitivity. The patient should not be burdened with serving as carrier of his own medical case history. Multi-generation electronic medical histories (including parents-grandparents) will enable the launching of predictive and preventive medicine. Furthermore, patients will know that they will receive the best diagnosis and treatment, since the physician's recommendations will be based on the pooled clinical experience of many physicians. Since the patient will control all access to his electronic health records, medical privacy will be increased rather than threatened.

c) Insurance carriers

Since all documentation of diseases and services rendered will be computerized, there will be no further need for manual issuing of claims for reimbursement. Paperless claim issuing/processing will be a computer function, associated with very large cost savings. Actuarial studies in health and life insurance will be greatly facilitated by the availability of better aggregate medical data.

d) Planners and administrators

Access to current and accurate statistical data will be important in government and the private sector. Public health services, drug safety as controlled by the Food and Drug administration, the Environmental Protection Agency and all other health protecting and social agencies will be able to improve their effectiveness by having access to a complete and accurate data bank of clinical events.

e) Medical educators

Medical schools will be able to teach with the help of real life clinical cases. Perhaps one of the most exciting new possibilities will be "anonymous prescriptive guidance." A group of clinical experts will be able to retrieve the current therapeutic habits of all physicians managing a given disease such as rheumatoid arthritis or hypertension. Such analyses will reveal the presence of a few obsolete or even outright incorrect treatments. Using the master computer center, the experts can send a message directly to those physicians who are in need of guidance to upgrade their care. This highly focused correction will be anonymous. Neither the national experts nor the erring physicians would be identifiable, an important aspect of constructive tutorial rather than punitive use of the technology.

f) Clinical medicine

The expected benefits to the science and practice of medicine will be large. Instant answers will become available to many medical controversies such as the exact value of low cholesterol diet, or exercise, or anticoagulation after an acute myocardial infarction. Thousands of such controversies will be answered by a national electronic pooled case history bank.

g) Health industry

Drug manufacturers will be able to study the indications, effectiveness and adverse reactions of their products as perceived by the practitioners. Pharmacists will be able to play a growing role in the health care system. With the support of the medical information system, they will contribute to patient education, so important in modern medicine.

VIII. STATE-OF-THE-ART

In airline reservations and in other areas of business and industry, there are numerous examples of highly successful information systems. The data processing technology is certainly ready for a single medical information system. Due to the growing knowledge deficit at the bedside, practicing physicians would appreciate the help offered by such a system. The recognized need for effective aid is great.

Research in computer-assisted diagnosis, computer-aided teaching have much to offer in the further enhancement of the benefits of such a national information system.

The cost of installing a national medical information system will be rather trivial in the light of cost reduction offered by paperless administrative and fiscal functions.

Medical privacy is a more serious problem However, enough research has been carried out recently to identify the ways for effective technical protection of the data and the ethical aspects of electronically handled confidential medical data have been extensively studied.

Perhaps the largest and most difficult task to be carried out before the installation of a national medical information system will be to orient the medical profession as well as the entire health care industry along with the patient community to accept such a national system. The aid of our communications media to prepare the country for a computer-supported practice of medicine will also be important. The role of the Congress in leading this country to better life and health in the 1990s by exploiting high technology will be critical.

Whereas the many successfully organized information systems indicate that judicious use of high technology is cost-effective and very helpful, we also have some less successful experiences which should be carefully considered. A regimenting, inefficient, ineffective, badly organized medical data system would not only waste our limited funds, but also polarize and prejudice the health care industry. Finally, it seems important to emphasize that hardware and software are available, but "mediware" (the experts in medical computing) is scarce. Implementing such a vast data system will require the involvement of the best intellects, the best planners and the best organizers. This will be the greatest challenge for medicine since the discovery of the microscope, but the rewards will be commensurate.

Mr. **Brown**. Doctor, I very much appreciate your testimony. You get directly to a point that seems to be the central point in a number of areas about how we facilitate change in a complex society with many actors and vested interests. You are suggesting we need a radically different approach here focusing on a public-private partnership which could plan, design, and presumably implement such a system. We have given thought to that institutional mechanism in many ways with the overall objective of upgrading the total economy of this country, and making our great industrial system work. We have not really resolved the problem of how to do it but the more we have knowledgeable persons such as yourself urging to us create a mechanism the public-private cooperation in securing this change, the closer we are going to get to achieving some things of that sort. I say that in complement to your testimony. But the next question is, knowing the medical field as you do and the hundreds of thousands of actors with vested interest, the doctors, the hospitals, the various other organizations that supply and serve this great system, what is the first step we would take in creating this institutional partnership aimed at producing the best for the country? It seems to me to be a gigantic problem in any realistic terms.

Dr. **Gabrieli**. If you look at the wall of this room where the spacemen are pictured, you see the achievement of some of the best brains of the country, and I think you face a similar immense task in medicine, to break the traditional approaches. Just to give you one additional practical experience as was mentioned earlier by Dr. Ball, our medical schools still resist the meaning of computerization. Most medical schools still admit students only based on college grades, while empathy, interest in the patient, and social sensitivity are very secondary considerations. Grades in organic chemistry make the decision who goes into medicine. With where we are going in the next 5 years, the ability to memorize is going to shrink in significance, but we are still continuing along the same way as we did in the past.

Mr. **Brown**. I am still not clear what this committee might recommend if we were to accept your thesis and say, now here is what we have to do. To give you an example, in wrestling with this problem for a number of years about the way to focus the Nation's capabilities beyond the utilization of our improved information technologies in general, I have labored and brought forth a proposal to set up a national information institute which would be a public-private institute which would be aimed at doing this kind of a job that you described for medicine for all fields. Actually it is an overly ambitious proposal. What would you say to setting up a national institute for health information systems with public-private participation at the level of board of directors which would be charged by congressional mandate with analyzing, planning, and implementing the best possible medical or health information systems for the Nation. Would that be a way to go about this sort of modeled-after concept? When we looked at the new technology of satellite communications we said we ought to be creating a new institutional arrangement which we will call Comsat, and it has produced a revolution in satellite communications. It is being run basically as a private enterprise today. I noticed we just appointed to the board of directors, the executive president of General Motors and I hope he will be more successful in Comsat than he has been in General Motors. But is this a model to set up a freestanding national institute with the power of Congress and the resources to develop this system for modernizing our health information systems for this country?

Dr. GABRIELI. I think that is an excellent suggestion. There is a great deal of legislative activity needed. You have to seriously rethink the problem of privacy and find some defense for that. The privacy of the patient, the doctor, the institution, the system must be kept. You have to rethink educational objectives with a computer-supported world in mind. You have to redirect clinical care which is computer supported. The whole insurance industry will be totally changed when there is a window available on health and illness. The drug manufacturing world will be altered completely by being able to follow their own products, side effects, effectiveness, and so on. We will change the whole health care industry. It will probably save enormous amounts of money which may be spent to better patient care.

About 22 or 23 percent of the medical dollar is currently spent on administrative functions. Most of it would be eliminated by computerization but the main thrust of all this will be better patient care. The patients will learn that an electronic record system is valuable to them. There was some talk this morning very tangentially about evolution of medical data. Fifty years ago we were fascinated by infectious diseases because they took 2 or 3 or 4 weeks to unfold. More recently we learned about diabetes, rheumatoid arthritis, chronic kidney diseases, genetic diseases, and the like which follow a 30- or 40-year cycle. The data collection for such cases is much more difficult.

There is a new concept emerging which is talking now about keeping several generations of information on file, your grandparents' records should be there, so that we can anticipate for which diseases you may run a high risk, such as coronary or kidney disease. Armed with this information, you can start preventive health care, a new field in medicine which depends entirely on data. Truly, a new world unfolds here in the 1980's. Congress could guide this country into a leadership position in the world so that American medicine will again be the pride of this country as it was 30 years ago.

Half of those same doctors are still practicing, and yet medicine is today a national liability simply because information technology has not been properly utilized.

Mr. BROWN. Doctor, your statement is tremendously exciting and challenging. As much at least as the concept of the space program to which you referred earlier. Yet a key ingredient in our great success in achieving triumphs in space, an ingredient I think we now have lost was produced by inspired leadership, a great president who announced great goals that challenged the people of America to a vision they had not seen before. Let me ask you what would happen if you were to approach the president of the American Medical Association and ask him to support such a great goal. Do you think he would give that kind of leadership to what you are suggesting here?

Dr. **Gabrieli**. As to the American Medical Association, I should not preempt their statement, but I am very aware of their planning of a national medical network. They are already very seriously thinking about it. We are currently organizing a national meeting to be held in November where we will ask all of the leaders of the field of medicine to explain why we are so much behind and what can we do to close the gap compared to other science and industry areas. We believe the climate has suddenly improved. There was a lot of progress made in medical computing. We know now how to enter medical records in English into the computer. We do not have to code manually. We know that physicians respond positively when they see their patient records quickly retrievable. I showed a cardiologist, after 2 years of computerization how successful he was with his coronary bypass surgery candidates and how successful he was with treating hypertension. He could compare his success rates with other cardiologists. When the other cardiologists looked at the system, they all wanted to participate. So I believe physicians are not so resistant, but we really did not have a very good system to offer. The system is emerging now. Right now is the time to think 5, 10, and 20 years ahead.

Mr. **Brown**. Dr. Gabrieli, I do not want to appear to be erudite, but a week or so ago I scanned a book called Computer Assisted Medical Decisionmaking by Dr. Homer Warner. Are you familiar with that?

Dr. **Gabrieli**. Certainly.

Mr. **Brown**. Does that represent the state of the art or is what I am seeing in that book atypical or typical of what the technology could do?

Dr. **Gabrieli**. Dr. Warner is a superb investigator and one of the leaders of the field, but that book does not represent the whole field. There are other similar important achievements, all within the last 2 or 2½ years.

Mr. **Brown**. And you are saying that you think that the medical profession would be willing to—willing to enter into a large-scale public-private participation partnership to try and move progress in this field forward rapidly.

Dr. **Gabrieli**. Upon careful planning I would be very optimistic, but I would be scared to come out with a poorly designed system. The past experience is that information systems were simultaneous attempts to control medicine. Those who have the data can control. I think part of the problem for medicine in this country is that these different, conflicting functions have not been separated as sharply as in, for example, the legal profession. Those who work to improve the quality of patient care are also supposed to worry about the costs. These are really conflicting interests. But a well-designed plan, sir, would be certainly extremely acceptable and could serve both goals separately.

Mr. **Brown**. The first step would be to seek some sort of a well-designed plan, I would think.

Dr. **Gabrieli**. Right.

Mr. **Brown**. This program, in any realistic terms, would have to be a 10- or 20-year program, it seems to me.

Dr. **Gabrieli**. Right.

Mr. **Brown**. But one in which we have a mechanism, instead of floundering for moving toward a goal.

Dr. **Gabrieli**. Exactly.

Mr. **Scheuer**. Would you buy 5 to 10 years?

Mr. **Brown**. Not if it took 7 years just to get a death index; I would not.

Dr. **Gabrieli**. You have to look at the long range, and you have to bring in new concepts, such as information, as a driver of medicine. For instance a regional medical data center in our concept should be the local information center for the whole community. When the annual summer infant diarrhea comes along, the regional data center should pick up the increase instantly. The original data center should recognize that two or three hospitals in the area have identified the micro-organism causing the diarrhea as well as what antibiotic was most successful. Then share it with all the local doctors. The system should be sensitive to local health influences. They should watch that old-age homes and senior-citizen buildings should not be built next door to a steel plant so that the old pulmonary emphysema patients would ride directly to the hospital. The increased frequency of carcinoma of the urinary bladder in a chemical factory should emerge at a time when the first three cases occur, not 20 years later when the lawsuits come in. That it is real-time, on-line communication of which Dr. Ball spoke. It should be available in the health care industry the same as it is in other segments of science and technology.

Mr. **Brown**. Doctor, your suggestions are imminently reasonable and rational. It seems to me there is an extremely strong case that can be made for the health profession to take the leadership in doing what you are suggesting. They are the ones who are recognized as leaders in every community. They have the resources. They have the knowledge and the best educated subgroup of the population. They can be pioneering the change which would revolutionize the whole country first in health and then in a host of other ways. Education would follow along and the whole society would end up being improved if what you are suggesting could be done. I am still stymied by the fact that I have not seen this kind of vision and leadership emanate from the medical profession.

Dr. **Gabrieli**. I am lecturing all over the world and spread this word. Let me give you another example.

Mr. **Scheuer**. We are going to have to ask the witness to concentrate his efforts in the United States.

Dr. **Gabrieli**. Let me present another dimension which is very much within the capabilities of such a concept. All doctors, all hospitals, all nursing homes, all national networks must be first fully protected in terms of privacy. Then there should be a national body of experts appointed to retrieve therapeutic directions in the whole country. For instance, retrieve all rheumatoid arthritis cases in the United States and study how they were treated, not 10 years ago, but yesterday. You can retrieve such data instantly. Then the experts recognize those doctors, perhaps in smaller communities, who are still treating rheumatoid arthritis with obsolete, outdated methods or outright dangerous methods. The experts may send a message through the network to unknown, unidentified physicians at the other end, on whose screens the next day will appear the appropriate paragraphs of the data bank saying that this particular drug is carcinogenic, do not use it any more. The doctor does not know exactly where the message came from, so there is no hostility attached to such guidance. Then you can go back and study how much you have improved the clinical care of that particular disease. So you can get focused education instead of holding forced education courses as currently we do where we teach only what we can handle comfortably and we have no measure of success in memorizing and so on. It is the most wasteful part of medical education currently that we force physicians to go to educational meetings instead of using new technology with a much higher impact.

We computerized a family physician's practice for exactly 1 year. Then we played back every word he used for that year in all his medical records, thousands and thousands of records, and we examined areas of "white spots" where his terminology was missing, indicating a gap in his knowledge. We found he is not very up to date on immunology because he did not use immunologic terms in his practice, yet he had multiple myeloma cases and other cases of immunopathology, so he had plenty of reason to use those, but he did not know them. We showed this to some leaders of medical education and they were very enthusiastic. They saw for the first time they could measure how well we teach through our system. If our family physician improves his knowledge in immunology, then the next time he is going to vaccinate a patient, he will remember that there is an immunal-allergic reaction possible. So teaching becomes now a transparent function, rather than throwing bottles in the ocean hoping somebody is going to find the bottle.

Mr. Brown. Dr. Gabrieli, I could spend a great deal more time going over possibilities that you have outlined. I think one of the values of these hearings is they put on the record information which you and our other witnesses are well aware of but which I think the Members of Congress are not aware of and the public even less aware of as to the tremendous beneficial changes that could be produced if we were to be able to overcome whatever problems have caused us to not fully utilize the capabilities that we have in this area. I am very grateful to you for your testimony.

Dr. Gabrieli. Thank you, sir.

Mr. Scheuer. I am going to ask you two questions, Dr. Gabrieli. The second one I am going to also ask to Dr. Ball. This is the penultimate question. I take it you feel that we are ready to build a national health information service?

Dr. Gabrieli. We are building one ourselves and we believe it possible.

Mr. Scheuer. What do you estimate the total cost to be when it is finished, when every major health institution is plugged into it and when half a million of our Nation's doctors are plugged into it? Who is doing the planning and should there be any further involvement of other groups, other institutions in the planning and finally how should such a system be marketed?

Dr. Gabrieli. First, allow me to address the question of cost. There is a priming cost to initiate a national medical information system which is probably in terms of hundreds of thousands, or at the most a few million dollars. As soon as the priming phase is over, the system would go into a positive balance, and we estimate about $20 to $30 billion per year is to be saved by computerization simply by reducing duplications. In medicine we write one record for the patient which is accurate because we use it for documenting our medical work, but another one is kept for the insurance company and a third one for various statistical purposes. We are motivated as physicians not to be accurate anywhere else except in our own records. I, for instance, very rarely write in the billing records accurate diagnoses, if they might prejudice the patient's future employability.

Mr. SCHEUER. Similarly hospitals tell us they have to keep entirely different books for the Federal Government, for the State government, and for the county government, and the insurance companies. What they would like to do is have a little room with thick carpets and lovely decorations and a computer terminal whenever any official from Federal, State, or local government or insurance companies wants to provide records they lead them into the computer room, show them where to push the button for another printout and say be our guest. Anything you want from us is right here. Now they cannot do that at the present time and I take it that reflects your dilemma of having a whole lot of different receivers of information wanting different information from you and I suppose different characteristics and different criteria and different standards.

Dr. GABRIELI. The physician is not playing games; it is in the interest of the patient. For instance when in New York City a famous experiment was carried out some 15 or 20 years ago. It was guaranteed to the pathologist who did necropsies that there would be no release of the medical diagnoses. A surge of the diagnosis of syphilis followed, an increase of something like 10 times because normally you do not want to embarrass the family by writing upon the death certificates that the diagnosis was syphilis. As a humanitarian commitment to our patient we sense a conflict between our medical judgment and the truth.

Mr. SCHEUER. Let me ask you to address the question. You have given us what the cost will be. You tell us we are in the process of creating this system. Are there any other groups that should be involved in the planning and once you have such a system—and maybe you have it now—how do we market it to these half million doctors around the country and to the 7,000 hospitals? How do we get the word out? How do we make them want it to enhance their own professionalism.

Dr. GABRIELI. We have the technology completely under our control now. What we have to do is to have it democratized, acceptable to our free enterprise system and our love of freedom instead of representing that this is what we all judge to be the best to the patient, the doctor, and for the system. The planning has to be very careful and very broad-based to include all aspects, so that, for example, insurance companies will not be embarrassed, or drug manufacturers will not be excluded, the pacemaker manufacturers can have the data they need. The data should be available to everybody, just as stockmarket values or gold prices are available. This should be the goal of the planning. If I would be given the task after today's experience, the first thing I would do is ask the

Congress for a bipartisan team to examine the problem and really understand all of the enormous ramifications. This team could then present a concept, totally new, in which every interest is equally considered. That would be automatically marketable, because the medical world is really very ready for it. They are waiting for it. Nobody likes the current pressure for better medicine by means of peer review, reexamination, relicensing, forced education. We would love to have a data system which we can use with confidence.

Mr. SCHEUER. Now let me ask my last question and perhaps Congressman Brown will have another question. We have been very frustrated for the last number of years with the degree to which the Food and Drug Administration is falling behind in the approval of new drugs. They are in the horse and buggy stage or in the quill pen stage. Drug companies are delivering tons of information to them. They do not have the sophisticated, trained personnel available even to go through the pages, to pagenate, to file or mark, much less to actually study them. As a result it takes anywhere from 10 to 15 years to get a new drug application pushed through the system at a cost of $50 to $75 million. American patients are denied life-enhancing and life saving drugs that are in use all over the world both in developed countries, Western Europe, Canada, Australia, New Zealand, Japan, as well as the developing countries. To me I have the feeling about FDA that you have about our country, they are fiddling with the existing system and that is not good enough. I asked 4 years ago in May of 1977 for the General Accounting Office to do a study of their decisionmaking process. It developed into a major study. It took them 3 years. They had researchers all over the world. They made a number of recommendations. In the process of the study they conferred with FDA and they got a degree of cooperation from FDA and they felt FDA now was at the point where they would improve their processing time 10 percent across the board for drugs and 15 percent for important drugs. To me that is nowhere nearly good enough. I think they should cut their time 75 or 80 percent. There is no reason why it has to take 10 to 15 years and cost $50 to $75 million and it should not be 10 or 15 percent, less it should be a fifth or a quarter. Can you see any application of computer sciences, any application of the way that you are now evaluating health implications, or carcinogens in the air and water and the work place; any theoretical application of computer sciences that would help the Food and Drug Administration make decisions far more rapidly than they do now and cut the time of the clinical investigation that now takes years and years and years to a comparatively brief period of time? Assuming they relied on postmarketing surveillance, and assuming they put a large number of people into this around the country, and assuming they had daily or weekly reports by doctors that would go into a central computer bank. I am not trying to design the system. I am asking you that in connection with this very serious national problem of delay of years and years and years of drugs that would marvelously benefit the American public were they available. Can we help FDA improve radically its decisionmaking process by the application of computer science across the board in its decisionmaking system?

Dr. **Gabrieli**. The answer is a very emphatic yes. Currently, one of the big problems of the FDA system of drug approval is the need for individual physicians to test a drug in phase II. Hundreds upon hundreds of patient records are submitted to the drug company. They abstract them. They analyze them. They do statistical summaries. They work it up for hundreds of thousands, even millions of dollars. Then everything is condensed into a small tiny, information package. Then it goes to FDA and they go through the whole procedure from beginning to end—starting with the doctors' records. They rerecord them; they recompute them. They reanalyze them. They are repeating the drug company's analysis because they do not trust the drug company. I think both of them should give up this function. Computers can absorb the doctors' records. Those computers can then condense the data. There in no human manipulation needed. The machinery could be programed with a great deal of FDA participation as well as drug manufacturers' participation. Then let the computer handle it from the moment the doctor makes the observation until the final FDA decision comes out.

The approval phase is not the only time when computers could play an important role. We know a story to illustrate the point. Six months ago, one of the drug companies had to inform all physicians that a very popular drug might cause hepatitis. Then the big question was: who knows what patients are on this drug? For us, the answer was the computer. We did it for our physicians. We requested the information instantaneously. Five minutes later, the computer typed a letter to each of the patients, "Come down and have a test within the next week." In sum, the safety of the pharmaceutical system would be enormously increased if we could have real time data access, rather than several year delays in implementing new policy.

Clinical experience with drugs could be greatly increased. Meanwhile, the almost paranoic pressure now on the FDA to prevent another thalidomide catastrophy in this country could be relieved with this new continuous surveillance capability. You may remember, sir, that when the thalidomide tradegy emerged a few years ago, we in the United States had to look to Australia, where they have an obstetric neonatal information network in Sidney and Melbourne and ask them to look up their data to insure that our pregnant patients here in the United States were not bringing drug-induced malformed babies into the world. We are at the point today, despite present technology, that when the Center for Disease Control suspects a new epidemiologic problem, such as toxic shock syndrome, the way to find information is to call friendly hospitals and ask them, "Did you see more of this?" This in not adequate, modern protection for a great medical and technological country. In genetics today, physicians take pictures and send them to experts, because there is no available data base. We are really trying to solve 1980 problems with 1700 methods.

Mr. **Scheuer**. Dr. Ball, do you remember my question?

Dr. **Ball**. I think Dr. Gabrieli addressed it so magnificently and so globally that I cannot add any other thing other than to say you wanted to know what other agencies or what other areas should be involved as we look at this and I think it is essential that we get the major forces of American medicine and American health care involved like the AMA, AHA, the Hospital Finance Management Association, the various Government agencies that are doing it, the professional societies such as the Society for Computer Medicine, the Government agencies such as National Library of Medicine. All of these do need to work together in the effort to develop a computerized medical information system that has national implication and that should have the brain power and force of those experts in the country who have thought about it such as Dr. Gabrieli has over the last 20 years and within our own community can take some of the responsibility for what impetus has happened over the last 2 years in furthering computers in medical use.

Mr. SCHEUER. This has been a remarkable day of hearings. You have kept us riveted to our chairs here. We are enthralled at the potential that you hold out for improvement in the health care system and reduction of cost in achieving a far higher quality of health care. Your testimony has been thoughtful, stimulating, creative, on the outer edges of moving our society and we are terribly grateful to you. You have been extraordinarily helpful to us. Thank you very much. The meeting is adjourned.

[Whereupon, at 12:45 p.m. the subcommittees adjourned.]

HEALTH INFORMATION SYSTEMS

WEDNESDAY, JUNE 3, 1981

House of Representatives, Committee on Science and Technology, Subcommittee on Science, Research and Technology; Subcommittee on Natural Resources, Agriculture Research and Environment,
Washington, D.C.

The subcommittees met, pursuant to call, at 9:30 a.m. in room 2325, Rayburn House Office Building, Hon. James Scheuer and Hon. Doug Walgren (chairmen of the respective committees) presiding.

Mr. Scheuer. The second day of hearings on the application of computer systems to health care will come to order.

We are here, of course, in an oversight capacity, not to discuss just a single piece of legislation. But it does seem relevant at this time to discuss some past efforts in this regard.

Major attempts by Congress to mandate the coordination of health statistics were made in 1974 in Public Law 93-353 and again in 1978 in Public Law 95-623.

This legislation places responsibility for coordinating efforts in health research, health statistics, epidemological studies and the assessment of health care technology, with the Secretary of Health, Education, and Welfare, now Health and Human Services.

These efforts are to be coordinated through the National Center for Health Statistics and the National Center for Health Care Technology.

It is regrettable to me that the Department of Health and Human Services was not here yesterday as we requested them to be, to give us an overview of how these mandates are being carried out within the Department. It is my understanding, however, that Dr. Edward Brandt, Assistant Secretary for Health of the Department will be appearing before us tomorrow and perhaps will be able to respond to this issue at that time.

Yesterday we received excellent testimony on the needs and benefits of such a system, benefits both to our getting a handle on health care costs and potential benefits in substantially improving the diagnostic capability of the individual physician.

Today we will look at the issues presented by and the potential problems involved with implementation of a coordinated health information system.

There are certain issues, such as personal privacy, which will be troublesome to us and which will be difficult to resolve.

The appropriate course to follow in assuring the effective implementation of such a service is yet an open question. How we resolve the problems of privacy is an open question. How we produce the involvement by the medical and other professional communities to move toward this CHIS is an open question.

Additionally, it is an open question as to whether we should pursue a purely legislative solution in the public sector alone or whether we employ some kind of voluntary public-private sector system.

It is these open questions that we intend to explore in the course of this hearing.

Our first witness will be Ms. Joanne Quan, director, data systems, health management system, New York State. She will be followed by a panel of experts from the private sector who will give us additional insights that they have achieved in areas of health information systems.

Now, we have a problem today, because there is a very important Democratic caucus. It will be commencing at about 10 minutes to 10. The subject of the caucus is on the Democratic position on President Reagan's tax program. Under the Democratic rules of the House, we cannot hold a hearing while the caucus is going on.

Now, we intend to take that admonition cum salis granum, with a large grain of salt, and we will be holding hearings, because that is going to be going on all morning. But Congressman Brown and I feel that we ought to show our faces over there.

So what we plan to do is hear Ms. Quan for about 15 minutes, until about 5 minutes to 10. Then we will recess until about 10:30. We should be back between 10:30 and 10:45. If you would be willing to wait until then, we will have some questions for Ms. Quan, I am sure, and then we can go ahead with the rest of the witnesses.

I regret we are imposing on the patience and good nature of the witnesses. But we just have been placed in a bind. When this scheduled hearing was set up, we had no knowledge that there would be a Democratic caucus this morning on such an important matter.

As I say, under the rules of the Democratic caucus, we cannot hold a hearing while the caucus is in session. We are going to shortcut that somewhat and come back and hope that no Democrat will file a formal objection.

So with those words, and our joint apologies and regrets on the imposition on the time of the witnesses and audience, too, who we are concerned about, if nobody has any violent objections, we will go ahead on that basis.

We will hear from Ms. Quan, her direct testimony, and then we will recess for about 30 or 40 minutes and come back here.

Before Ms. Quan begins, I would like to recognize my distinguished colleague, Congressman Brown, who has been an early supporter of the coordinated health information system.

Mr. BROWN. Thank you. I have no additional comments.

Mr. SCHEUER. Also, we have now been joined by Congressman Doug Walgren, who is the joint chairman of this session, the chairman of our sister subcommittee.

Mr. SCHEUER. Ms. Quan, we are delighted to have you here today. Your testimony will be printed in full in the record, so in the next 12 or 15 minutes, why don't you chat with us informally, if you would like.

If you are familiar with the testimony that we had yesterday, if anybody has talked to you about it, you are more than welcome to address anything that transpired here yesterday, any thoughts that were expressed either by members or witnesses.

With that, let us repeat our welcome to you, and the floor is yours.

STATEMENT OF JOANNE QUAN, DIRECTOR, DATA SYSTEMS, HEALTH SYSTEMS MANAGEMENT, NEW YORK STATE

Ms. **Quan**. Congressman Scheuer, Congressman Brown, Congressman Walgren, members of the Subcommittee on Natural Resources, Agriculture Research and Environment, and members of the Subcommittee on Science, Research, and Technology, I am Joanne Quan, deputy director of the New York State Office of Health Systems Management's Division of Health Care Financing.

I am pleased to be here today to speak to you about the needs for a coordinated health information system.

Prior to assuming my duties in finance, I served as the director of the New York State data systems development project which has been funded by the Health Care Financing Administration of the Department of Health and Human Services under a State demonstration grant.

During my tenure as director, we developed and implemented just such a health information system which has been in full operation since 1980. I appreciate the opportunity to share my experiences on this project with you.

The development of mechanisms to contain and monitor hospital costs while assuring access to high quality care has been one of the primary goals of the New York State Office of Health Systems Management, OHSM, since its inception in 1977. To carry out this broad mandate, a set of basic yet vital facts must be available to that office.

As you know, one of the obstacles to more effective control of the spiraling costs of health care has been inadequate statistics. In many cases, the information is itself fragmented or not available or when available not comparable.

The New York statewide planning and research cooperative system, more commonly known by its acronym, SPARCS, is a State-developed and operated systematic investment in the future which will enable us to fulfill our statutory health care mandates.

SPARCS receives, stores, and processes inpatient data from all hospitals in New York State. It is a unified, comprehensive health care information network which supports and links, through integrated data, the functions of resource planning, financing, and surveillance of hospital services in New York State.

Since SPARCS draws on both institutional and patient statistical, medical, and financial facts, hospital costs and activities can be matched against the types of patients a facility treats and the range of services provided there.

We consider SPARCS to be long overdue as a critically needed support system to assist in our efforts to improve the State health care system. The Federal Government has viewed the project as a national model for other States in the country in terms of uniform hospital reporting, a comprehensive health care data base and an integrated management information system.

Thus, SPARCS has far-reaching ramifications both within and outside the State of New York.

The basic sources of data from SPARCS include annual hospital financial and statistical reports as well as inpatient billing and discharge information. All acute care hospitals in the State are required to submit data from four documents to OHSM: a uniform billing form; a uniform discharge data abstract; the Federal annual hospital report; and a State supplement to that report.

These four documents replace a myriad of forms formerly used by hospitals.

As a result of this program, New York is the first State in the Nation to have all major third-party payors utilizing a uniform hospital bill and the first to have a common statewide data set for the Professional Standards and Review Organizations.

These firsts highlight in my mind ways in which Federal and State health care information policies should converge and diverge.

The uniform bill provides hospitals with a single billing document for medicare, medicaid, Blue Cross, commercial carriers, and workers compensation, thus eliminating dozens of claims forms hospitals once had to complete. SPARCS information is extracted from the UBF-1 after payment is made to the hospital and this procedure takes advantage of the edits, corrections, and computer tape transfer performed by the insurance companies, thus promoting accuracy of information and reducing the amount of automation that is required by SPARCS. And in addition, the postpayment data collection will not interfere with cash flow to hospitals by the insurers.

Today the PSRO data collection activities and SPARCS are working together so that there is only one reporting mechanism for both programs in all hospitals.

For approximately 85 percent of all cases in New York State hospitals already automate that discharge data and rather than introduce a new form, OHSM accepts computer tapes of this information wherever available. As a result, each institution need only collect medical discharge information once, for its own purposes, for the PSRO, and for SPARCS.

With these events in mind, I would urge the committee to carefully weigh the factors of systemwide uniformity versus State flexiblilty in the following manner.

A Federal minimum hospital data set should be met by all States. This information is vital to establishing a comparable and comprehensive national data base for Federal and State planning, analysis, and monitoring of hospital services. In addition, this core data can be used as a foundation for a State to build upon for its own information system.

States should be allowed to submit federally mandated information in a specified computer tape format rather than be tied to a specific document form. This type of technological flexibility frees a State from a Federal hard copy form so that it may develop its own statewide forms which not only meet the Federal Government's requirements but also the data needs of multiple health organizations in that particular region.

States should be allowed to develop their own data collection system to meet the Federal requirements as well as their own informational needs. Thus States may identify collection mechanisms which best meet and/or take advantage of processing systems already in place in their own area.

I think it is important to expand upon this last point in terms of States opting for voluntary versus mandatory data collection systems.

While some States have met with success in utilizing a voluntary approach to consolidated health information systems, I do not think accomplishments of the New York mandatory system should be minimized or discounted.

The success of SPARCS, of course, depends on the accuracy and completeness of the data gathered. To insure that all hospitals in the State are included in this system, participation in SPARCS is mandatory in New York.

I believe the sheer size of the hospital industry in New York, with widely diverse reporting practices and capabilities, necessitated this approach. There are approximately 300 hospitals in our State. There are 6 Blue Cross plans in New York, 57 medicaid county offices, 8 medicare fiscal intermediaries, and dozens of commercial carriers, not to mention self-pay and charity cases. These payors range from basic to sophisticated in their reporting procedures and operations. And in the case of the discharge abstract, there are hospitals with in-house computer capability, some with contracted services and some with only manual operations.

The bills and abstracts, although linked, will be submitted to SPARCS on separate forms. We will be processing almost 7 million individuals' records per year. It is our intention to assure that the discharge abstracts be matched to the billing records and that all patient files be linked to the 300 institutional files.

Within the framework of this diverse and enormous system and industry, we felt that mandatory participation would be essential for SPARCS.

New York's experience has been that it is extremely difficult to obtain cooperation of all the involved groups without a State mandate.

A mandatory system is the only way that complete data could be obtained since a significant number of hospitals would be unlikely to cooperate without the regulatory requirement.

The State's regulatory authority allows the definition of a uniform data set with uniform data definitions. Without such a mandate, hospitals would use their own sets of data elements with their own definitions.

The State can require a data submission schedule for all hospitals. Without such a time limit, it is likely there would be very great problems with the timeliness of data submission.

Last, a State data system has numerous advantages in the areas of privacy and confidentiality. The State authority of such a system provides for the promulgation of regulations that include penalties for violations. State regulations allow for a process that is more open to public accountability. And many institutions and organizations would not cooperate with the voluntary system because of the lack of official regulations for the protection of privacy and confidentiality.

This last objective concerning confidentiality proved to be one of the most difficult issues in New York and became a major point of contention between the State and Federal Government.

From the beginning of the SPARCS program, the State sought to design regulations which would protect patient privacy. Although patients' names are not collected, OHSM recognizes that other data elements are also sensitive. At the same time, we did not want to employ methods which would result in SPARCS data being inaccessible, and therefore of little or no value to all concerned.

Therein lay the dilemma. We had to find a balance between preserving confidentiality of individual records and the legitimate need to know about hospital activities.

Accordingly, New York has taken several precedent-setting steps. The State has developed SPARCS privacy regulations which are not only regarded as quite stringent by many but are also the first set of specific confidentiality procedures in the country to govern a hospital data system. These regulations define two classes of data requests—deniable and nondeniable. Access to nondeniable matter will be processed and disclosed consistent with the State freedom of information law.

Deniable data requests are those asking for specific data elements which by themselves or in combination might enable one to identify an individual or institution. All requests for deniable information must be carefully reviewed by the Data Protection Review Board. This public review body is broadly representative of the community, industry, and government, and is appointed by the Commissioner of Health. The board makes recommendations to the Commissioner on the release of information. While the Commissioner may reverse the decision of the board, the board retains the authority to overturn the Commissioner's decision by a two-thirds vote.

We believe that this system of checks and balances guards the rights of individuals while providing access to needed information.

The Health Care Financing Administration of HHS took issue with this approach in 1979. HCFA indicated to us that its interpretation of Federal statute gives the Secretary of HHS unfettered access to all data on patients covered by titles V, XVII, and XIX of the Social Security Act. These Federal beneficiaries represent almost 70 percent of the patients covered in New York. HCFA also maintained that its significant financial support of SPARCS should result in a system which provided HHS with immediate and automatic retrieval of this data.

For these reasons, HCFA requested a change in the New York State privacy and confidentiality regulations which would allow HCFA to bypass the Data Protection Review Board for these data. OHSM upheld its position and months of negotiations followed.

I should mention that the entire grant also was in jeopardy at this point.

Finally a compromise was reached whereby HCFA is given access to data when Federal law requires disclosure of SPARCS data from providers, fiscal intermediaries, the State, and others.

The Data Protection Review Board is now functioning extremely well. It is our strong feeling that these privacy procedures should serve as a model for other States. The review process in New York does not, in fact, hinder appropriate access to information. Instead it provides a uniform safeguard to protect individual privacy.

Perhaps the most essential ingredient to New York's success to date has been the cooperative element the State has intertwined with this mandatory program. SPARCS has in fact represented a unique union between the public and private sector to meet the mandates of the present and to plan for the future. Its design and development has involved a major effort by government to invite active participation from the community and industry.

These joint efforts have been integral to the establishment of a statewide information system to serve numerous health care programs.

As a result, SPARCS has received wide support among various organizations that have contributed to its development and continuation including the Hospital Association of New York State, all the health systems agencies, all the PSRO's and commercial insurers.

That public-private partnership gives every evidence that substantial benefits will be reaped as each organization begins to learn about each other through SPARCS reports.

The investment of these groups in SPARCS as a major decision-making tool is illustrative of the system's importance to industry and Government alike.

It is my strong belief that the New York statewide planning and research cooperative system will prove to be a national model as a support program for a more effective, efficient and responsive health care system.

Thank you.

[The prepared statement of Ms. Quan follows:]

NEW YORK STATE
DEPARTMENT OF HEALTH
DAVID AXELROD, M.D., Commissioner

Remarks:

Joanne M. J. Quan
Deputy Director
Office of Health Systems Management

before the Subcommittee on
Natural Resources, Agriculture, Research
and Environment
and the Subcommittee on
Science, Research and Technology

on
The New York Statewide Planning and
Research Cooperative System (SPARCS)

June 3, 1981

Congressman Scheuer, Congressman Walgren, Members of the Sub-Committee on Natural Resources, Agriculture Research and Environment, and Members of the Subcommittee on Science, Research and Technology, I am Joanne Quan, Deputy Director of the New York State Office of Health Systems Management's Division of Health Care Financing.

I am pleased to be here today to speak to you about the needs for a "Coordinated Health Information System". Prior to assuming my duties in financing, I served as the director of the New York State Data Systems Development Project which has been funded by the Health Care Financing Administration of the Department of Health and Human Services under a state demonstration grant. During my tenure as director, we developed and implemented a health information system which has been in full operation since 1980. I appreciate the opportunity to share my experiences on this project with you.

The development of mechanisms to contain and monitor hospital costs while assuring access to high quality care has been one of the primary goals of the New York State Office of Health Systems Management (OHSM) since its inception in 1977. To carry out this broad mandate, a set of basic yet vital facts must be available to the office. As you know, one of the obstacles to more effective control of the spiralling costs of health care has been inadequate statistics. In many cases, the information is either fragmented or not available or, when available, not comparable.

The Statewide Planning and Research Cooperative System, more commonly known by its acronym, SPARCS, is an OHSM developed and operated systematic investment in the future which will enable us to fulfill our statutory health care mandates. SPARCS receives, stores, and processes inpatient data from all hospitals in New York State. It is a unified, comprehensive health care information network which supports and links, through integrated data, the statutory functions of resource planning, financing, and surveillance of hospital services in New York State. Since SPARCS draws on both institutional and patient statistical, medical and financial facts, hospital costs and activities can be matched against the types of patients a facility treats and the range of services provided there.

The value of a coordinated information system has long been recognized. In fact, the current State project builds upon the work of a broad-based voluntary group named the Data Consortium, composed of statewide representatives from hospitals, insurance companies, physician groups, local planning agencies and government. The Consortium's organization in 1975 was an acknowledgement of the pressing need for an integrated data system to support all phases of health care delivery in New York State. It was, and still is, a commonly held belief that this program would be essential to both industry and government in support of their mutual goal of assuring high levels of care at reasonable cost to the citizens of New York State.

We consider SPARCS to be long overdue as a critically needed support system to assist in our efforts to improve the State health care system. The federal government has viewed the project as a national model for other states in the country in terms of uniform hospital reporting, a comprehensive health care data base and an integrated management information system. Thus, the Statewide Planning and Research Cooperative System has far-reaching ramifications both within and outside the State of New York.

The basic sources of data from SPARCS include annual hospital financial and statistical reports as well as inpatient billing and discharge information. All acute care hospitals in the State are required to submit data from four documents to OHSM:

- Uniform billing form
- Uniform discharge data abstract
- Federal Annual Hospital Report (AHR)
- State supplement to AHR

This type of information has been collected by the State for years. However, SPARCS represents an innovative approach to gathering health care data in that it does it on a consolidated, statewide and uniform basis with wide application for multiple organizations and agencies. The documents and the SPARCS data sets were, in fact, developed in conjunction with a diverse number of groups outside state government. All the organizations that served on the original Data Consortium are still represented on our advisory body, the Council on Hospital Information Policy.

SPARCS reporting forms will replace a myriad of forms which were formerly used by hospitals. Hospitals reporting to SPARCS is structured for streamlining and minimal distruption to existing systems. The AHR Report and the State Supplement will replace and consolidate about half a dozen hospital documents which are now submitted every year. Hospitals will have fewer reports to complete and will no longer be faced with conflicting surveys, since all the SPARCS reports are based on uniform codes, definitions and principles.

As a result of this program, New York is the first state in the nation to have all major third party payors utilizing a uniform hospital bill and the first to have a common statewide data set for the Professional Standards and Review Organizations. The way in which these "firsts" were accomplished in New York highlight, in my mind, where federal and state health care information policies should converge and diverge.

In the case of the hospital billing form, efforts in our State appeared in conflict with another national demonstration activity to develop a uniform bill. After analyzing the other form, called UB 16, we found that to meet the data needs of the major payors in New York, two additional attachment sheets would be required. This was highly undesirable, since we knew from experience that multiple sheet documents have a way of disconnecting, and holding up processing. And, for the purposes of timely reimbursement and adequate cash flow, hospitals wanted to insure expedited processing. With the backing of major payors and the industry, the State pursued its alternative, known as UBF-1, which is a one page document meeting all requisite data needs. At the State's insistence, the Health Care Financing Administration finally agreed to accept UBF-1 as an alternative model in New York, since it met federal reporting requirements.

Today, UBF-1 serves as a reporting document for SPARCS as well as the claims form which hospitals can use for all insurance companies in New York. The uniform bill provides hospitals with a single billing document for Medicare, Medicaid, Blue Cross, commercial carriers and Workers' Compensation--thus eliminating dozens of claim forms hospitals once had to complete. SPARCS information is extracted from UBF-1 after payment is made to the hospital. This procedure takes advantage of the edits, corrections and computer tape transfer performed by the insurance companies, thus promoting accuracy of information and reducing the amount of automation required by SPARCS. In addition, the post payment data collection will not interfere with cash flow to hospitals by the insurers.

Although there was no comparable national discharge data abstract form, the development of this document also demonstrated where state and federal programs may conflict -- this time at a local level. For the most part, each Professional Standards and Review Organization in New York State (with 17 PSRO areas) had been gathering the same information, but according to its own unique form or computer format. The federal authorizing legislation for PSROs permitted this fragmentation. Further, the PSROs wanted to maintain their own data systems, even though they would be duplicative of the more comprehensive SPARCS program.

Today the PSRO data collection activities and SPARCS are working together so that there is only one reporting mechanism for both programs in each hospital. Again, we chose to use existing resources to the greatest extent possible. For approximately 85 percent of all cases in New York State, the hospitals already automate the discharge data. Rather than introduce a new form, OHSM accepts computer tapes of this information wherever available. As a result, each institution need only collect the medical discharge abstract information once -- for its own purposes, for the PSRO, and for SPARCS.

With these events in mind, I would urge the Committee to carefully weigh the factors of a systemwide uniformity versus state flexibility in the following manner:

- A federal minimum hospital data set should be met by all states. This information is vital to establishing a comparable and comprehensive national data base for federal and state planning, analysis and monitoring of hospital services. In addition, this core data can be used as a foundation for a state to build upon for its own information system.

- States should be allowed to submit federally mandated information in a specified computer tape format rather than be tied to a specific document form. This type of technological flexibility frees a state from a "hard-copy form" so that it may develop statewide forms which not only meet the federal government's requirement but also the data needs of multiple health care organizations in that particular region.

- States should be allowed to develop their own data collection system to meet the federal requirements as well as their own informational needs. Thus, states may identify collection mechanisms which best meet and/or take advantage of processing systems already in place in their own area.

I think it is important to expand upon this last point in terms of states opting for voluntary versus mandatory data collection systems. While several states have met with success in utilizing a voluntary approach to consolidated health information programs, I do not think accomplishments of the New York mandatory system should be minimized or discounted.

The success of SPARCS, of course, depends on the accuracy and completeness of the data gathered. To ensure that all hospitals in the State are included in this system, participation in SPARCS is mandatory in New York. I believe the sheer size of the hospital industry in New York -- with widely diverse reporting practices and capabilities -- necessitated this approach. There are approximately 300 hospitals in our State. In the case of the uniform bill, we wanted to collect the data post-payment wherever possible to take advantage of edits, corrections and tape reduction by third parties. However, there are six Blue Cross Plans in New York State, 57 Medicaid county offices, 8 Medicare fiscal intermediaries, and dozens of commercial carriers, not to mention self-pay and charity cases. These payors range from basic to sophisticated in their reporting procedures and operations. And, in the case of the discharge abstract, there are hospitals with in-house computer capability, some with contracted abstracting services and some with only manual operations.

We estimate that there are approximately 2.9 million hospital discharges per year. Based on prior history, we can expect 1.3 bills per patient, or approximately 3.8 million bills per year. In other words, once the system is in operation we will be processing almost seven million individual records per year. The bill and abstracts, although linked, will be submitted to SPARCS on separate forms. It is our intention to assure that discharge abstracts be matched to billing records and that all patient files be linked to the 300 institutional files.

Within the context of this diverse and enormous system and industry, we felt that mandatory participation would be essential for SPARCS:

- New York's experience has been that it is extremely difficult to obtain cooperation of all the involved groups without a state mandate.
- A mandatory system is the only way that complete data could be obtained since a significant number of hospitals would be unlikely to cooperate without the state mandate.
- The state mandate allows the definition of a uniform data set with uniform data definitions. Without such a mandate hospitals

would use their own sets of data elements with their own definitions.

- The state can mandate a data submission schedule for all hospitals. Without such a mandate it is likely that there would be very great problems with the timeliness of data submission.
- A state mandated system has a firmer base for long range funding, since it does not have to depend on voluntary contributions or assessments for its operating funds.
- A state mandated system has numerous advantages in the areas of privacy and confidentiality.
  a. The state authority of such a system provides for the promulgation of regulations that include penalties for violations.
  b. State regulations allow for a process that is more open to public accountability.
  c. Many institutions and organizations would not cooperate with a voluntary system because of the lack of official regulations for the protection of privacy and confidentiality.

This last objective proved to be one of the most difficult issues in New York and became a major point of contention between the state and federal government. From the beginning of the SPARCS program, the State sought to design regulations which would protect patient privacy. Although patients' names are not collected, OHSM recognizes that other data elements are also sensitive. At the same time, we do not wish to employ methods which will result in SPARCS data being inaccessible and, therefore, of little or no value to all concerned. Therein lay the dilemma. We had to find the balance between preserving confidentiality of individual records and the legitimate need to know about hospital activities.

Accordingly, New York has taken several precedent-setting steps. The State has adopted SPARCS privacy regulations, which are not only regarded as quite stringent by many but are also the first set of specific confidentiality procedures in the country to govern hospital data systems. The major purposes for which data from SPARCS may be used, as defined in these regulations, are:

- Financial studies,
- Rate setting,
- Surveillance,
- Health planning and resource allocation studies,
- Epidemiology,
- Research studies, and
- The monitoring of its own data by a hospital.

These regulations further define two classes of data request, deniable and not-deniable. Access to non-deniable matter will be processed and disclosed consistent with the State Freedom of Information Law. Deniable data requests are those asking for specific data elements which by themselves, or in combination, might enable one to identify an individual or institution. All requests for deniable information will be carefully reviewed by the Data Protection Review

Board. This public review body is broadly representative of the community, industry and government and is appointed by the Commissioner of Health. The Board makes recommendations to the Commisioner on the release of information. While the Commissioner may reverse the decision of the Board, the Board retains the authority to overturn the Commissioner's decision by a two-thirds vote. We believe that this system of checks and balances guards the rights of individuals while providing access to needed information.

The Health Care Financing Administration of HHS took issue with this appraoch in 1979. HCFA indicated to us that its interpretation of federal statute gives the Secretary of HHS unfettered access to all data on patients covered by Titles V, XVII and XIX of the Social Security Act. These federal beneficiaries represent almost 70 percent of the patients treated in New York. HCFA also maintained that its significant financial support of SPARCS should result in a system which provided HHS with immediate and automatic retrieval of this data. For these reasons, HCFA requested a change in the New York State privacy and confidentiality regulations which would allow HCFA to by-pass the Data Protection Review Board for these data. OHSM upheld its position and months of negotiations followed. Finally, a compromise was reached whereby HCFA is given access to SPARCS data when federal law requires disclosure of such data from providers, fiscal intermediaries, the state and others.

The Data Protection Review Board is functioning well. At its monthly meeting, the Board is generally dealing with two to three requests for deniable data. The Board has not yet denied any request that has come before it; nor has the Commissioner overturned any decision of the Board. It is our strong feeling that these privacy procedures should serve as a model for other states. The review process in New York does not, in fact, hinder appropriate access to information. Instead, it provides a uniform safeguard to protect individual privacy.

To date, the SPARCS program has been federally funded. In the fall of 1977 the New York State Office of Health Systems Management was awarded a $1.1 million grant from the Health Care Financing Administration to establish the Data Systems Development Project during 1978. During the first year, $300,000 was spent on research and development of the SPARCS program. The 1979 grant totaled some $3.2 million -- of which $1.9 million was devoted solely to SPARCS. Of the toal grant for 1980, $2.4 million was used for the further development and full implementation of the SPARCS system. During 1981 SPARCS will complete the phase out of funding from the federal government, amounting to approximately $1 million this year. Continued and future funding of SPARCS will be based on a fee assessed on all hospitals, where this fee may be recovered from, and thus apportioned to, the various third party payors. This financing structure, whereby the costs associated with this information system are recognized as an allowable expense for reimbursement, is a model which may be replicated in other states as well as by the federal government.

We estimate that it will cost approximately $4 [illegible] ~~billion~~ to run SPARCS annually, once it is operational. Compared to the almost $7 billion that New Yorkers spent last year on hospital care, $4 million is a mere fraction--less than .06 of one percent. This is a small price to pay to know just what that $7 billion bought.

From this investment, we will be able to:

- Obtain up-to-date information on hospital average lengths of stay and costs by patient types to determine reimbursement and utilization standards.
- More closely monitor utilization review determinations to ensure that appropriate care is delivered.
- Identify unusual cases of morbidity and mortality patterns for public health purposes.
- Determine how various treatment patterns affect hospital costs.
- Analyze comparative hospital utilization and productivity profiles for regional planning decisions.
- Consolidate comprehensive information in SPARCS to eliminate the dozens of overlapping data collection activities which are routinely carried out by numerous organizations.

In the hope of reducing the volume of expected requests and to utilize the full potential of the system by data easily available, a SPARCS annual publication series is being developed for issuance this summer. This series will make use of the 1980 data base through the development of a set of standard reports which will be of value to a wide spectrum of health information users. Development of the formats of these reports began in 1980 and is being coordinated through a health information users advisory committee, representative of all major health data users in the State. In addition to the annual publication series, each hospital providing data is issued a standardized processing report that informs the facility of the acceptance rate for abstract data that have entered the SPARCS system from their facility. OHSM also prepares a quarterly report on the uses of SPARCS data. Clearly, any national or local system of this sort should provide regular and informative feedback to both the industry and the public.

Finally, I think the most essential ingredient to New York's success to date has been the cooperative element the state has intertwined with this mandatory program. SPARCS has represented a unique union between the public and private sector to meet the mandates of the present and to plan for the future. Its design and development has involved a major effort by government to invite active participation from the community and industry; these joint efforts have been integral to the establishment of a statewide information system to serve numerous health care programs. As a result, SPARCS has received wide support among various organizations that have contributed to the development and continuation of the program, including the Hospital Association of New York State, Health Systems Agencies, Professional Standards and Review Organizations and commercial insurers.

Moreover, that public/private partnership gives every evidence that substantial benefits will be reaped as each organization begins to learn more about the other through SPARCS reports. The investment of these groups in SPARCS as a major decision making tool is illustrative of the system's importance to industry and government alike. It is my strong belief that the New York Statewide Planning and Research Cooperative System will prove to be a national model as a support program for a more effective, efficient and responsive health care system.

Data Elements from Uniform Billing Forms (UBF-1) for SPARCS

ID and MEDICAL DATA

Data Element #	Critical Elements	Non-Critical Elements
3.	Medical Record Number	
4.	Admitting Number	
5.	Admission Date	
9.	Patient's Date of Birth	
11.	Sex	
13.	Address - Street (Patient)	
14.	Address - City (Patient)	
15.	Address - County (Patient)	
16.		Address - State (Patient)
17.	Zip Code (Patient)	

MEDICARE PAYMENT INFORMATION

54.	Medicare Provider Number	
55.		Medicare Health Insurance Claim #
64.		Medicare Part A Number of Covered Days
66.		Medicare Part A Covered Days Extension
67.		Medicare Part A Coinsurance Number of Days
69.		Medicare Part A Coinsurance Days Extension
77.		Medicare Non-Covered Days
79.		Patient Responsibility
85.		Medicare Amount Reimbursed

BLUE CROSS PAYMENT INFORMATION

89.	Blue Cross Provider Number	
95		Blue Cross Claim Certificate Identification Number One

BLUE CROSS PAYMENT INFORMATION (cont'd)

97.		Blue Cross Plan Number One
101.		Blue Cross Claim Certificate Identification Number Two
103.		Blue Cross Plan Number Two
107.		Blue Cross Full Days One
110.		Blue Cross Full Days Two
119.		Blue Cross Non-Covered Days
120.		Blue Cross Billed Paid
121.		Blue Cross Patient Responsibility

COMMERCIAL PAYMENT INFORMATION

122.	Federal Tax Number	
124.		No Fault/Worker's Compensation
128.		Commercial Policy Number One
129.		Commercial Insurance Company Name
129.A	Insurance Company Code	
*138.		Commercial Room and Board
*139.		Commercial Room and Board Rate
*140.		Commercial Room and Board Extension
141.		Commercial Ancillary Service Days
143.		Commercial Ancillary Extension
144.		Commercial All Inclusive Days
146.		Commercial All Inclusive Extension or Hospital Charges
148.		Commercial Non-Covered Days
149.		Billed/Paid (Commercial)
150.		Commercial Patient Responsibility

MEDICAID PAYMENT INFORMATION

151.	Medicaid Provider Number	
152.		Locator Code
153.		Recipient Identification Number
*154.		Agency Code
155.		Rate Code

MEDICAID PAYMENT INFORMATION (cont'd)

156.		Special Program Codes
157.A		Resource Code
157.		Resource Amount
160.		Posted Charges Amount
161-62.	Resubmission Adjustment/Void Code	
163.		Original Claim Reference Number
*174.		Medicaid Full Days
*175.		Per Diem Rate
*176.		Medicaid Full Days Extension
177.		Medicaid Other (Include Part B)
178.		Patient Participation
179.		Medicaid Non-Covered Days
180.		Billed (Net Medicaid Claim)
181.		Prior Third Party(s)

ITEMIZED CHARGE SECTION

182.		Blood Pints Furnished
186.	Total Charge for Blood	
189.	Accommodation Days	
190.	Accommodation Rate	
191.	Accommodation Code	
192.	Accommodation Total Charge	
193.	Accommodation Non-Covered Charges	
194.	Ancillary Service Codes	
195.	Ancillary Total Charges	
196.	Ancillary Non-Covered Charges	
197.	Total of Blood, Accommodation and Ancillary Charges	
*198.		Total of Non-Covered Charges

OTHER ELEMENTS

199.	Discharge Date
201.	Patient Discharge Status
202-03.	Statement Covers Period From/Thru

OTHER ELEMENTS (cont'd)

*207.	Accident Type Code
208.	Stay Approved Thru
209.	Stay Denied Effective
214.	Carve Out Days

NOTE: An asterisk (*) denotes data elements which have the potential for development of critical edit routines.

UNIFORM HOSPITAL REPORTING

Pursuant to the authority vested in the State Hospital Review and Planning Council by Section 2803 of the Public Health Law, Part 405 of Article 2 of Subchapter A of Chapter V, Title 10 (Health) of the Official Compilation of Codes, Rules and Regulations of the State of New York, is hereby amended to be effective upon filing with the Secretary of State, as hereinafter indicated:

New Sections 405.28 and 405.29 are hereby added to read as follows:

405.28 UNIFORM BILL. *(a)* Bills for inpatient health services rendered by a hospital shall be on such uniform bills as *set forth in paragraph (b).* Hospitals shall be responsible for submitting to the Department data from such uniform bills as *indicated by the asterisked items on the form set forth in paragraph (b).* Where facilities are either currently using their own computer facilities to process and maintain such data or those with contracted services to process such data, such data shall be submitted on computer tape. Such data shall be provided for all patients discharged. The Commissioner may waive the requirement that a facility submit ancillary charge data to the extent that a hospital can show that it is presently without an ancillary charge structure. The Commissioner shall be responsible for protecting the confidentiality *and privacy* of data related to patient care and for assuring that the design of the system will protect that confidentiality *and privacy in accordance with regulations to be issued after public hearing and at least 21 days prior to collection of any data by the Department under this Section.*

(b) Uniform Bill:

UNIFORM HOSPITAL REPORTING

Pursuant to the authority vested in the State Hospital Review and Planning Council by Section 2803 of the Public Health Law, Part 86 of the Administrative Rules and Regulations as contained in Subchapter K, Chapter II, Title 10 (Health) of the Official Compilation of Codes, Rules and Regulations of the State of New York, is hereby amended to be effective upon filing with the Secretary of State, as hereinafter set forth:

Subdivisions (f) and (g) are hereby added to Section 86-1.3, to read as follows:

86-1.3 (f) Data required to be filed with the Department pursuant to Section 405.28 of this Title shall be submitted according to the specified format for at least 80% of all discharged patients within 60 days from the end of the month of patient billing and for at least 95% of all discharged patients within 180 days from the end of the month of patient billing. Wherein each of two successive quarters either of these criteria is not met, the Commissioner may reduce the current rate for the next calendar quarter by one percent except where the facility demonstrates that the delay in submission of the data is beyond its control.

86-1.3 (g) Data required to be filed with the Department pursuant to Section 405.29 of this Title shall be submitted according to the specified format for at least 95% of all discharge patients within 60 days from the end of the month of patient discharge. Wherein each of two successive quarters this criterion is not met, the Commissioner may reduce the current rate for the next calendar quarter by one percent except where the facility demonstrates that the delay in submission of the data is beyond its control.

The foregoing amendments were approved at a meeting of the State Hospital Review and Planning Council held on the day of , 1978, for adoption upon the approval of the State Commissioner of Health.

Acting Executive Secretary
State Hospital Review and Planning Council

(Rev. 9/13/78)

CODING METHOD | MEDICAL RECORD # | ADMITTING NO. | ADMIT DATE | HOUR | TYPE

TIENT NAME - LAST, FIRST, M.I. | BIRTH DATE | AGE | SEX | RACE

WN OF RESIDENCE | CITY | CNTY STATE | ZIP CODE

LICENSE NO

LICENSE NO

LICENSE NO

LICENSE NO

N DIAG UE | ADMITTING DIAGNOSIS

N DIAG DE | PRINCIPAL DIAGNOSIS/NATURE OF ILLNESS

IN PROC. DE | DATE | PRINCIPAL SURGICAL OR OBSTETRICAL PROCEDURE

ADMITTING SOURCE

PRIMARY REIMBURSEMENT

SECONDARY REIMBURSEMENT

HER DIAGNOSIS CODES

OTHER PROCEDURE CODES/DATES

ADDITIONAL PROCEDURE CODES/DATES

	DAYS CERT	DATE CERT.	REVIEW COORD. IDENT. NO.	CARVED OUT DAYS	RETRO IMP	REASON FOR DENIAL	DENIAL APPEAL'D	REVIEW PHYSICIAN IDENT NO	UTILIZATION REVIEW INFORMATION
1									CERTIFICATION PROCESS
2									DAYS ASSIGNED AT ADMISSION
3									NORMS UTILIZED
4									LEVEL
5									TOTAL DAYS CERTIFIED
6									TOTAL REVIEWS
									NUMBER EXTENSIONS APPROVED
									EXTENSION DENIED
9									
10									

DISCHARGE DATE | HOUR | STATUS

PROVIDER ID NO | LOC CODE | RECIPIENT IDENT. NO. | AGENCY

TYPE ALT CARE REQ DATE

IFY THAT THE CERTIFICATIONS ON THE REVERSE APPLY TO THIS BILL AND ARE MADE A PART HEREOF:

NEW YORK STATE
DATA DISCHARGE ABSTRACT
DDA-1

The foregoing amendments were approved at a meeting of the State Hospital Review and Planning Council held on the day of , 1978, for adoption upon the approval of the State Commissioner of Health.

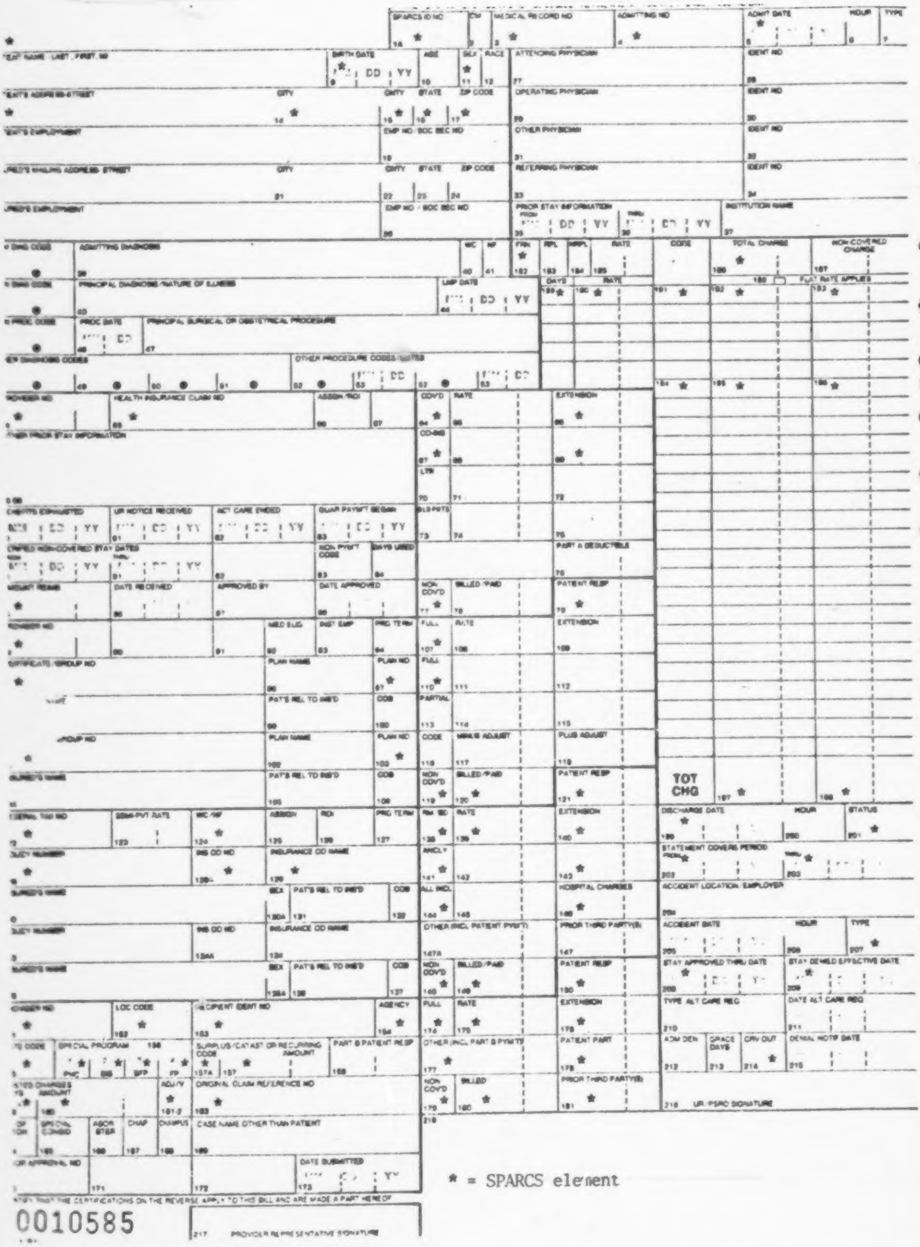
Acting Executive Secretary
State Hospital Review and Planning Council

(Rev. 9/13/78)

Uniform Discharge Abstract Elements

1. Coding Method
2. Medical Record Number
3. Admitting Number
4. Admit Date
5. Admit Hour
6. Admit Status
7. Zip Code
8. Age
9. Sex
10. Race or Ethnic Group
11. SPARCS Hospital Identification Number
12. License Number of Attending Physician
13. License Number of Operating Physician
14. License Number of Other Physician
15. Admitting Diagnosis Code
16. Principal Diagnosis Code
17. Principal Procedure Code
18. Date of Principal Procedure
19. Other Diagnosis Code (4 occurrences)
20. Other Procedure Code (4 occurrences)
21. Other Procedure Date (4 occurrences)
22. Length of Stay Indicator
23. Discharge Date
24. Discharge Hour
25. Disposition of Patient
26. Type Alternate Care Required
27. Date Alternate Care Required
28. Transfer Status
29. Primary Reimbursement
30. Secondary Reimbursement
31. Total Acute Certified Days Used
32. Transaction Code
33. Total Certified Alternate Care Days Used

(Effective 6/1/81)



0010585

* = SPARCS element

STATE OF NEW YORK
DEPARTMENT OF HEALTH OFFICE OF HEALTH SYSTEMS MANAGEMENT
TOWER BUILDING ● THE GOVERNOR NELSON A. ROCKEFELLER EMPIRE STATE PLAZA ● ALBANY, N.Y. 12237
DAVID AXELROD, M.D.
Commissioner
RICHARD A. BERMAN
Director

December 13, 1979

Forms Being Replaced By SPARCS Documents

Basically, SPARCS will be composed of four source reports: the Uniform Bill (UBF-1), the Uniform Discharge Data Abstract (DDA-1), the SHUR reports, and the State supplement to SHUR.

1) UBF-1 and Report of Eligibility replace the following inpatient billing, eligibility or admission forms.

a. for Medicare -

HCFA 1453
HCFA 1453-A

b. for Blue Cross Plans -

Albany:
H4A - Notice of Admission Form
H5 - Billing Form

Syracuse:
CL 50 - Notice of Admission Form
25M-85477-10/79 - Billing Form

Rochester:
F-712 - Notice of Admission Form,
F-43 - Hospital Billing Form,
[illegible] - Health Insurance Coverage Form, Coordination of Benefits Form

Utica:
HP-CL-13-C - Billing Form
HC-101-401 - Notice of Admission Form

Buffalo:
H1206 - Notice of Admission Form
H1237 - Billing Form
H146 - Additional BC Benefits for Medicare Cases
H1262 - Major Medical Claim Form

New York City:
HAC 33 - Non-Member Billing Form
HAC 74 - Inter-Plan Bank Billing Form
HAC 103 - Member Billing Form
HAC 487 - Coordination of Benefit Form

Upstate All Plans:
IPSBB.3-1

c. for Commercials

HIF-69
HAP-4 (and its variations)
All other forms used by commercial payors

d. for Medicaid

W220-B
UBF-1 (previously used for MMIS billing)
2140

e. Others

Workers' Compensation Billing Forms
No Fault Billing Forms .

2) The discharge data abstract:

a) Replaces forms currently being used to report NYSHUR data to the State including the DDA-1.

b) Utilizes existing hospital systems wherever possible.

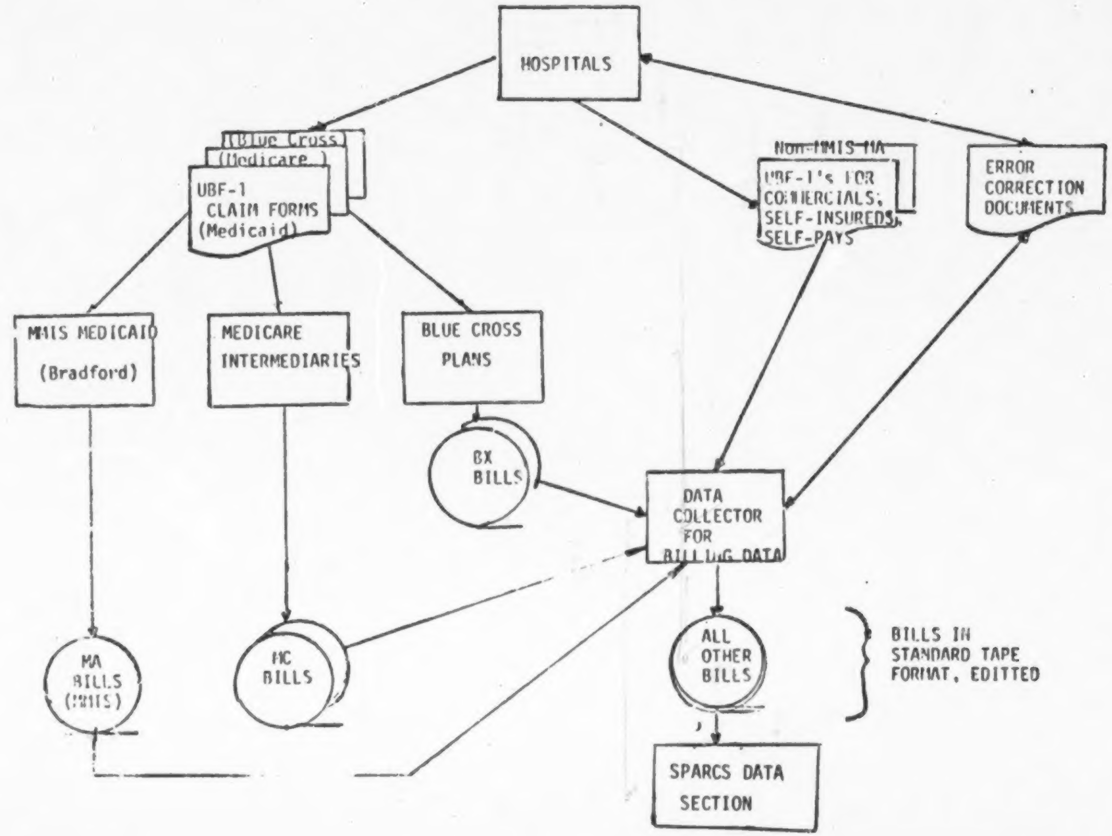
3) The SHUR manual replaces:

a) The NYS Hospital Uniform Financial Report.

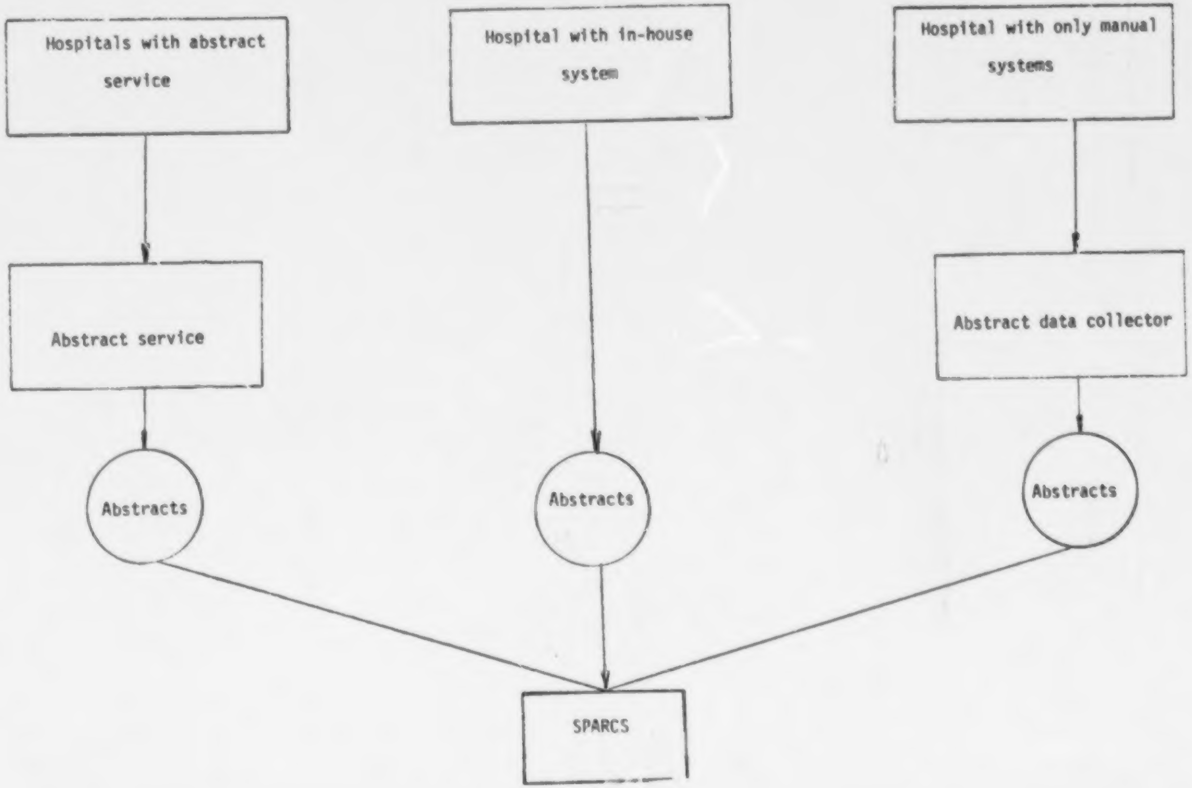
4) The State Supplement to SHUR will replace:

a) The NYS Hospital Uniform Statistical Report.
b) The Health Facilities Component of the Cooperative Health Statistics System.
c) Trending Survey.
d) State Salary Survey.
e) PRD10, Report on Per Diem Reimbursable Expense.
f) PRD13, Cost Allocation Adjustment Report.
g) Rate Settlement Sheets

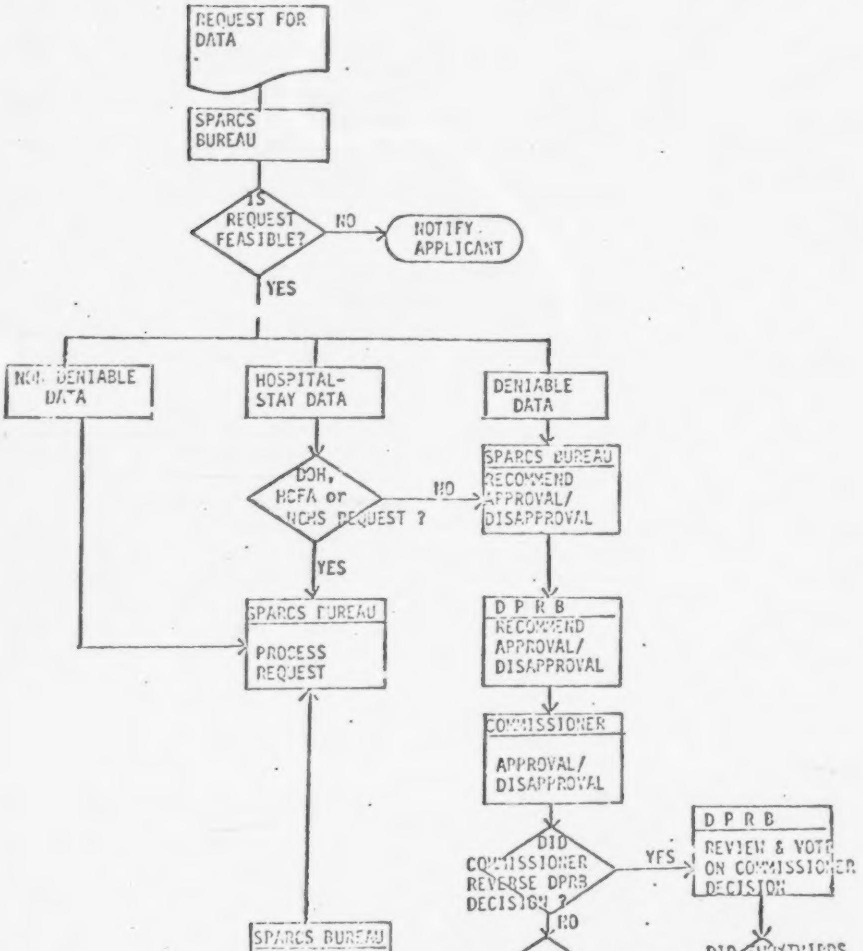
BI [illegible] COLLECTION


HOSPITALS
Blue Cross
Medicare
UBF-1
CLAIM FORMS
(Medicaid)
Non-MMIS MA
UBF-1's FOR
COMMERCIALS;
SELF-INSUREDS;
SELF-PAYS
ERROR
CORRECTION
DOCUMENTS
MMIS MEDICAID
(Bradford)
MEDICARE
INTERMEDIARIES
BLUE CROSS
PLANS
BX
BILLS
DATA
COLLECTOR
FOR
BILLING DATA
MA
BILLS
(MMIS)
MC
BILLS
ALL
OTHER
BILLS
BILLS IN
STANDARD TAPE
FORMAT, EDITTED
SPARCS DATA
SECTION

ABSTRACT DATA COLLECTOR


Hospitals with abstract service
Hospital with in-house system
Hospital with only manual systems
Abstract service
Abstract data collector
Abstracts
Abstracts
Abstracts
SPARCS

SPARCS DATA REQUEST REVIEW PROCESS


REQUEST FOR DATA
SPARCS BUREAU
IS REQUEST FEASIBLE?
NO
NOTIFY APPLICANT
YES
NON DENIABLE DATA
HOSPITAL-STAY DATA
DENIABLE DATA
DOH, HCFA or NCHS REQUEST ?
NO
YES
SPARCS BUREAU RECOMMEND APPROVAL/ DISAPPROVAL
DPRB RECOMMEND APPROVAL/ DISAPPROVAL
COMMISSIONER APPROVAL/ DISAPPROVAL
SPARCS BUREAU PROCESS REQUEST
DID COMMISSIONER REVERSE DPRB DECISION ?
YES
DPRB REVIEW & VOTE ON COMMISSIONER DECISION
NO
SPARCS BUREAU ARRANGE TO PUBLISH REQUEST
YES
REQUEST APPROVED ?
YES
DID TWO-THIRDS OF DPRB OVERRIDE COMMISSIONER ?
NO
NOTIFY APPLICANT
NO
COMMISSIONER DECISION STANDS

(5) that the medical staff organization shall be in accordance with requirements specified under this Part;

(6) stating the terms by which the managing authority may hire and discharge staff of the hospital, including physician employees;

(7) stating if the managing authority is to employ a qualified hospital administrator to act as the chief executive officer of the hospital;

(8) stating the duties and powers of the chief executive officer employed by the managing authority;

(9) specifying the terms and procedures by which the managing authority may make recommendations to the governing body concerning the medical staff organization.

Historical Note

Sec. filed May 25, 1978 eff. May 25, 1978.

405.28 Uniform bill. (a) Bills for inpatient health services rendered by a hospital shall be on such uniform bills as set forth in Appendix C-2, *infra*. Hospitals shall be responsible for submitting to the department data from such uniform bills as indicated by the asterisked items on the form set forth in Appendix C-2, *infra*. Where facilities are either currently using their own computer facilities to process and maintain such data or those with contracted services to process such data, such data shall be submitted on computer tape. Such data shall be provided for all patients discharged. The commissioner may waive the requirement that a facility submit ancillary charge data to the extent that a hospital can show that it is presently without an ancillary charge structure. The commissioner shall be responsible for protecting the confidentiality and privacy in accordance with regulations to be issued after public hearing and at least 21 days prior to collection of any data by the department under this section.

(b) Hospitals shall notify all patients that they are complying with the terms of this section by making available a copy of the patient notification letter (Appendix C-4, *infra*) to each patient or patient's representative upon admission.

Historical Note

Sec. filed Oct. 26, 1978; amd. filed Mar. 13,
1980 eff. Mar. 13, 1980.

405.29 Uniform discharge abstract. (a) All hospitals shall file for each patient discharged such uniform discharge abstracts as set forth in Appendix C-3, *infra*. Hospitals shall be responsible for submitting to the department data from such uniform discharge abstracts as indicated by the asterisked items on the form set forth in Appendix C-3, *infra*. Where facilities are either currently using their own computer facilities to process and maintain such data or those with contracted services to process such data, such data shall be submitted on computer tape. Such data shall be provided for all inpatients discharged. The commissioner shall be responsible for protecting the confidentiality and privacy of data related to patient care and for assuring that the design of the system will protect that confidentiality and privacy in accordance with regulations to be issued after public hearing and at least 21 days prior to collection of any data by the department under this section.

(b) Hospitals shall notify all patients that they are complying with the terms of this section by making available a copy of the patient notification letter (Appendix C-4, *infra*) to each patient or patient's representative upon admission.

Historical Note

Sec. filed Oct. 26, 1978; amd. filed Mar. 13,
1980 eff. Mar. 13, 1980.

405.30 Disclosure of data contained in the uniform bill and uniform discharge abstract to prevent unwarranted invasions of personal privacy. (a) *Definitions.* For the purposes of this section, the following terms shall have the following meanings:

(1) *New York State Statewide Planning and Research Cooperative System (SPARCS)* shall mean a statewide centralized health care system which incorporates data obtained from, among other sources, the uniform bill and uniform discharge abstract submitted to the department by hospitals pursuant to sections 405.28 and 405.29 of this Part.

(2) *Deniable individual stay data*, except as provided in paragraph (3) of this subdivision, shall mean data pertaining to a particular individual's hospital stay that contain one or more of the following deniable data elements which, if disclosed, would constitute an unwarranted invasion of personal privacy: medical record number, admit number, admit date, discharge date, date(s) of surgery, third-party payor patient identification number, address, birthdate, physician identification, accident date and hospital identification.

(3) *Individual stay data* shall mean data pertaining to six or more hospital patients which do not include any of the deniable data elements referred to in paragraph (2) of this subdivision. The following shall not constitute deniable data elements: month and year of admission, month and year of discharge, length of stay, number of pre-operative days, number of post-operative days, class of payor, census tract location of patient, age of patient at one-year intervals for patients one year old or older, age of patient at one-week intervals for patients less than one year old, physician specialty, number of attending physicians, presence or absence of an accident, and hospital reimbursement peer group. Any data pertaining to fewer than six hospital patients shall be deemed to constitute deniable individual stay data.

(4) *Hospital stay data* shall mean individual stay data and, in addition, the deniable data element of hospital identification.

(5) *Aggregated data* shall mean a statistical tabulation of hospital patient records, with no single grouping or tabulation, to be based upon fewer than six hospital patient records. Where groupings are based upon fewer than six records, such groupings will be eliminated or combined with other groupings.

(6) *Deniable aggregated data* shall mean aggregated data which include one or more of the deniable data elements referred to in paragraph (2) of this subdivision.

(7) *SPARCS bureau* shall mean a bureau within the New York State Office of Health Systems Management whose functions and responsibilities are elaborated in subdivision (c) of this section.

(8) *Data protection review board (DPRB)* shall mean a board whose members are appointed by the commissioner and whose functions and responsibilities are elaborated in subdivision (d) of this section.

(b) *Purpose of SPARCS*. (1) SPARCS is designed to contribute to the goal of providing high quality medical care at reasonable cost to the inhabitants of the State by serving as an information source for organizations and agencies seeking to promote the efficient delivery of health care services.

(2) Consistent with paragraph (1) of this subdivision, the purposes for which data from SPARCS may be used include the following:

(i) financial studies — investigation of alternate means of paying for hospital care to bring about a more cost-effective system of hospital financing;

(ii) rate setting — modeling of rate policies and calculating of reimbursement rates for hospitals;

(iii) surveillance — surveillance of hospitals including investigation of fraud and abuse, medical audit and utilization review;

(iv) health planning and resource allocation studies — the rational allocation of limited resources to health care, provision of adequate health care and article 28 approval processes;

(v) epidemiology — identification of exceptional morbidity or mortality patterns for more in-depth study. Studies of prevalence and incidence of diseases can be indicated by these data;

(vi) research studies — investigation into a number of health care research studies, including utilization, variations on length of stay, disease dynamics and health economics, for patient use patterns.

(c) *SPARCS Bureau*. (1) Functions.

(i) All requests for data from SPARCS shall be submitted to the SPARCS Bureau.

(ii) The SPARCS Bureau shall review all requests for data in order to insure that the request is technically feasible in terms of the ability of SPARCS to produce the required data.

(iii) All requests for data which are not technically feasible shall be returned to the applicant with a statement containing the reason why the request is being returned.

(iv) All requests for individual stay data or aggregated data which do not constitute deniable individual stay data, hospital stay data or deniable aggregated data and which are technically feasible shall be processed within a reasonable time.

(v) The SPARCS Bureau shall review all requests for deniable indivudal stay data, hospital stay data and deniable aggregated data in order to determine:

(*a*) whether the purpose of the request is consistent with the purposes for which data from SPARCS may be used. In making its review, the SPARCS Bureau will not be limited to a review of the ostensible purpose of the request, as stated in the applicant's formal request for data;

(*b*) whether the applicant is qualified to undertake the intended study; and

(*c*) the utility of each study for which data is requested.

(vi) The SPARCS Bureau shall not recommend for approval requests for deniable individual stay data, hospital stay data or deniable aggregated data unless it is satisfied that:

(*a*) the purpose of the request is consistent with the purposes for which data from SPARCS may be used;

(*b*) the applicant is qualified to undertake the intended study; and

(*c*) the applicant requires such data and is able to insure that patient privacy is protected.

(vii) After completing its review, the SPARCS Bureau shall forward all requests for deniable aggregated date, hospital stay data and deniable individual stay data together with its recommendations, the results of its review and all supporting data to the Data Protection Review Board.

(2) The SPARCS Bureau shall publish monthly or cause to be published monthly in the *State Register* and may publish or cause to be published, in such trade, industry or professional publication as the bureau may select, a listing of all recipients of deniable individual stay data, hospital stay data or deniable aggregated data and the purposes for which the data has been utilized.

(d) *Data Protection Review Board (DPRB)*. (1) Membership.

(i) The DPRB shall consist of 15 members to be appointed by the commissioner for terms of three years, except that the initial appointments to the DPRB shall be made for terms as follows:

(*a*) five members shall be appointed for a term of two years;

(*b*) five members shall be appointed for a term of three years;

(*c*) five members shall be appointed for a term of four years.

Upon expiration of these terms, the commissioner shall appoint members of the DPRB to full three-year terms.

(ii) In making appointments to the DPRB, the commissioner shall consider recommendations submitted by statewide constituencies represented in subparagraph (ii) of paragraph (2) of this subdivision.

(iii) Members shall serve without remuneration.

(2) Functions. (i) Subject to subdivision (g) of this section, the DPRB, by a majority vote of its members, shall approve requests for deniable individual stay data, hospital stay data and deniable aggregated data, subject to ratification by the commissioner.

(ii) The DPRB shall be representative of the following groups:

(*a*) Federal government (1 member);
(*b*) State government (1 member);
(*c*) private third-party payors which are corporations organized in accordance with article IX-C of the Insurance Law (1 member);
(*d*) commercial insurers (1 member);
(*e*) hospital providers (2 members);
(*f*) health systems agencies (1 member);
(*g*) professional standards review organizations (1 member);
(*h*) consumers (3 members);
(*i*) medical societies (1 member);
(*j*) bar associations (1 member);
(*k*) medical record associations (1 member); and
(*l*) health care academic researchers (1 member).

(iii) The DPRB shall not approve any request for deniable individual stay data, hospital stay data or deniable aggregated data, unless it is satisfied that:

(*a*) the request is technically feasible in terms of the ability of SPARCS to produce the requested data;
(*b*) the purpose of the request is consistent with the purposes for which data from SPARCS may be used;
(*c*) the applicant is qualified to undertake the intended study; and
(*d*) the applicant requires such data and is able to insure that patient privacy is protected.

(iv) Notwithstanding anything contained in subparagraph (iii) of this paragraph, the DPRB shall approve requests from the Health Care Financing Administration (HCFA) of the United States Department of Health and Human Services for deniable individual stay data, individual stay data, aggregated data, hospital stay data or deniable aggregated data when Federal law requires disclosure of data pertaining to patients covered by titles V, XVIII or XIX of the Social Security Act.

(v) The DFRB may approve an application requesting that data from SPARCS be supplied on a periodic basis for a predetermined time not to exceed three years. Notwithstanding any prior approval given to an applicant to receive data on a periodic basis, the DPRB may at any time require an applicant to submit a new application to be approved pursuant to this regulation.

(3) Procedures. (i) All requests for data to be reviewed by the DPRB shall be entered in a log.

(ii) The DPRB shall meet monthly or as necessary. Prior to each meeting, DPRB members will receive a summary description of each request on that meeting's agenda, along with copies of all previous reviews and recommendations pertaining to that request.

(iii) No later than 21 days prior to the date of its monthly meeting, the DPRB shall notify or cause to be notified any person or agency filing a written request, such request to be renewed yearly in December, for summary descriptions of each request for data on that meeting's agenda. The DPRB may charge, for such summary description, a fee which shall consist of the cost of preparation, handling and postage for the summary.

(iv) At its monthly meeting, the DPRB shall vote on all requests for data which have been submitted to DPRB members more then 21 days prior to the date of its meeting. Notwithstanding the above, the DPRB may vote to defer a request for data for one month. The DPRB may defer a request for data only once.

(v) After each meeting of the DPRB, each request for data which has not been deferred shall be forwarded to the commissioner for his ratification or disapproval. Any request which has not been deferred and which has not been approved by a majority of the members of the DPRB shall be deemed to have been disapproved by the DPRB.

(e) The commissioner shall not ratify any request for deniable individual stay data, hospital stay data or deniable aggregated data unless he is satisfied that:

(1) the request is technically feasible in terms of the ability of SPARCS to produce the requested data;

(2) the purpose of the request is consistent with the purposes for which data from SPARCS may be used;

(3) the applicant is qualified to undertake the intended study; and

(4) the applicant requires such data and is able to insure that patient privacy is protected.

(f) Notwithstanding anything contained in subdivision (e) of this section, the commissioner shall ratify requests from HCFA for deniable individual stay data, individual stay data, aggregated data, hospital stay data or deniable aggregated data when Federal law requires disclosure of data pertaining to patients covered by titles V, XVIII or XIX of the Social Security Act.

(g) The commissioner shall make his decision whether to ratify or disapprove the determination of the DPRB within 10 business days after receiving from the DPRB the request for data.

(h) If the decision of the commissioner is to disapprove of the DPRB determination, he shall return the request for data to the DPRB which shall reconsider the request at its next meeting. If, after such reconsideration, two thirds of the members of the DPRB shall vote to overturn the commissioner's decision, the request shall be processed in accordance with the DPRB's determination notwithstanding the objection of the commissioner. If two thirds of the members of the DPRB do not vote to overturn the commissioner's decision, the request shall be processed in accordance with the commissioner's decision.

(i) *Requests for data by the Department of Health, by the Health Care Financing Administration (HCFA) of the United States Department of Health and Human Services, or by the National Center for Health Statistics.*

(1) Requests for hospital stay data, individual stay data and aggregated data.

(i) Notwithstanding anything contained in this section to the contrary, all requests for individual stay data, aggregated data and hospital stay data from the Department of Health, from HCFA or from the National Center for Health Statistics shall be furnished.

(ii) The SPARCS Bureau shall notify the DPRB of all such requests.

(2) Requests from HCFA for deniable individual stay data or deniable aggregated data.

(i) Deniable individual stay data and deniable aggregated data pertaining to patients covered by titles V, XVIII and XIX of the Social Security Act shall be furnished as required by Federal law.

(j) *Access to and purging of data.* (1) Examples of entities which may receive data from SPARCS pursuant to this section include the following:

(i) State Departments of Health, Social Services and Insurance;
(ii) third-party payors;
(iii) health systems agencies;
(iv) professional standards review organizations;
(v) hospitals;
(vi) State and local hospital associations;
(vii) Department of Health, Education and Welfare; and
(viii) medical societies.

(2) Notwithstanding anything contained in this section to the contrary, a hospital has the right to receive or inspect all data pertaining to its own patients for the period of time they remained patients at that hospital.

(3) No individual stay data will be retained beyond seven years. The address of patients shall be converted into a geographical code prior to entry into SPARCS.

(4) All source material received by the department and used to enter data into SPARCS will be subject to these regulations. All such source material will be destroyed in accordance with State law within one month of tape acceptance.

(5) All contracts or agreements entered into between the department and any person or entity who supplies data to SPARCS must insure that any such data which has been collected solely for submission to SPARCS is to be destroyed 30 days after acceptance by the department.

(k) "Requests for data." (1) Requests for data may be submitted on a standard form to be supplied by the SPARCS Bureau. All requests for data must contain the following information:

(i) the specific nature of data requested;
(ii) the particular tape format or report format desired;
(iii) the time period within which the data are desired; and
(iv) for data to be supplied more than once, the frequency with which data are to be supplied.

(2) Requests for individual stay data or aggregated data which do not consitute deniable individual stay data, hospital stay data or deniable aggregated data must contain an assurance that no attempt will be made to identify any specific individuals, physicians or providers of services about whom data are supplied.

(3) For all requests for deniable individual stay data, hospital stay data and deniable aggregated data, the following additional information must be provided:

(i) the nature of the study for which the data is requested;
(ii) a general description of any research leading up to the request;
(iii) the qualifications of the applicant to undertake the study;
(iv) the measures the applicant proposes to take to insure that patient privacy is protected; and
(v) specific citations to any applicable law which should be considered as part of the application.

(4) All requests for deniable individual stay data, hospital stay data or deniable aggregated data must contain the following assurances and promises:

(i) Only those persons in the request will have access to the data.
(ii) The data will be used only for the purposes stated in the request.
(iii) No deniable individual stay data, deniable aggregated data or hospital stay data will be released to any other person or entity without prior written authorization pursuant to this regulation.
(iv) That no attempt will be made to use any data supplied to identify any specific patients unless the data supplied are to be used only for legally authorized surveillance of providers of health services or utilization review and specific authorization for such use has been given pursuant to this section.

(5) (i) Any applicant who provides specific provider identification numbers in his request for data must furnish, as part of his application, proof of notification to all such providers of his request.

(ii) Any provider so notified shall have the right to submit comments to the SPARCS Bureau. Such comments must be included with any data pertaining to the provider which is disclosed to the applicant.

(6) In addition to any other sanction or penalty as provided by law, any person who violates any provision of this regulation or any promise or provision contained therein, shall be liable pursuant to the provisions of the Public Health Law.

(l) *Security.* (1) The commissioner shall designate, in writing, those employees of the SPARCS staff authorized to have access to the data bank. Steps shall be taken to control access to the data bank through the use of systems software and security procedures designed to protect data against unauthorized access. The commissioner shall appoint certain employees of the SPARCS staff to be data security officers who shall recommend data security rules and procedures to the commissioner who, after review, shall publish the rules and procedures.

(2) In addition to any other sanction or penalty as provided by law, any employee of the department who willfully violates this regulation or any other rule or procedure pertaining to the disclosure of any material collected pursuant to sections 405.28 and 405.29 of this Part shall be deemed to have committed an act of misconduct and shall be disciplined in accordance with the provisions of the Civil Service Law.

Historical Note

Sec. filed June 20, 1979, repealed, new filed Aug. 16, 1979; amd. filed Mar. 13, 1980 eff. Mar. 13, 1980.

405.31 Council on hospital information policy. (a) Definitions. For the purposes of this section, the following terms shall have the following meanings:

(1) *New York Statewide Planning and Research Cooperative System (SPARCS)* shall mean a statewide centralized hospital data system which incorporates data obtained from, among other sources, the uniform bill and uniform discharge abstract submitted to the department by hospitals pursuant to sections 405.28 and 405.29 of this Part.

(2) *Council on Hospital Information Policy (CHIP)* shall mean a council consisting of representatives of the major hospital data producers, collectors and users whose purpose is to advise the department on matters relating to hospital health care data. The council shall meet at least four times in each full calendar year.

(3) *SPARCS Bureau* shall mean a bureau within the New York State Office of Health Systems Management whose functions and responsibilities are delineated in section 405.30 of this Part.

(4) *Data Protection Review Board (DPRB)* shall mean a board whose members are appointed by the commissioner and whose functions and responsibilities are delineated in section 405.30 of this Part.

(b) *Membership.* (1) The CHIP shall consist of 14 members, to be appointed by the commissioner for terms of three years, except that the initial appointments to CHIP shall be made for terms as follows:

(i) five members shall be appointed for a term of two years;
(ii) five members shall be appointed for a term of three years; and
(iii) four members shall be appointed for a term of four years.

Upon expiration of these terms, the commissioner shall appoint members of CHIP to full three-year terms.

(2) The CHIP shall be representative of the following groups, which may recommend individuals to be appointed by the commissioner; such appointments shall not be unreasonably withheld:

(i) the hospital industry (3 members);
(ii) private third-party payors and commercial insurers (3 members);
(iii) professional standards review organizations (3 members);
(iv) health systems agencies (3 members); and
(v) hospital care academic researchers (2 members).

(3) A majority vote of the total membership of the CHIP shall be required in order to take any council action.

(4) Members shall serve without remuneration.

(c) *Functions.* (1) The CHIP shall advise the commissioner on matters relating to hospital health data policy including the following:

(i) the establishment of new hospital data collection systems, including the formulation of regulations governing such systems, and the development of efficient and effective data collection methodologies;

(ii) the maintenance and/or modification of SPARCS; and

(iii) the preparation of general purpose reports which address the common information requirements of data users.

(2) The CHIP shall review annually the requests that have been made for SPARCS data and shall make recommendations to the commissioner with respect to:

(i) the need to modify, add or delete specific data and information items based upon consideration of the actual operational needs of SPARCS; and

(ii) changes that would make the system for processing requests more efficient.

(3) Consistent with section 405.30 of this Part, the CHIP shall advise and assist the SPARCS Bureau and the DPRB:

(i) by providing advice and guidance relating to:

(*a*) policy issues of concern to the commassioner involving SPARCS or the DPRB; and

(*b*) proposed regulation changes involving SPARCS or the DPRB;

(ii) by providing advice, with respect to specific requests for SPARCS data.

Historical Note

Sec. filed Mar. 13, 1980 eff. Mar. 13, 1980.

405.32-405.1017 [*Reserved*]

405.1018-405.1019

Historical Note

Secs. filed June 15, 1976; repealed, filed July 25, 1977 eff. July 25, 1977.

405.1020 Compliance with State and local laws. The hospital is in conformity with all applicable State and local laws.

(a) *Standard; licensure of hospital.* The hospital, in any State in which State or applicable local law provides for the licensing of hospitals is (1) licensed pursuant to such law, or (2) approved, by the agency of the State or locality responsible for licensing hospitals, as meeting the standards established for such licensing.

(b) *Standard; licensure or registration of personnel.* Staff of the hospital is licensed or registered in accordance with applicable laws.

SPARCS DATA ELEMENTS

Attached is a listing of SPARCS data elements. Please review this list and determine if your request contains deniable elements. If a deniable element is being requested, use "SPARCS Request Form Involving Deniable Data"; if no deniable elements are being requested, use "SPARCS Request Form Involving Non-deniable Data".

The data elements are also defined by format. The format describes the data element field by size and type, i.e., 10x means the field is ten spaces, and the 'x' means that the field can contain a combination of numbers and letters.

KEY: X= Alphanumeric Format
N= Numeric Format
()= Occurrences

SPARCS DATA ELEMENTS

UNIFORM BILLING FORM
ID AND MEDICAL DATA

	DENIABLE	FORMAT
Medical Record Number	X	10X
Admitting Number	X	7X
Admission Date (Month and year only are non-deniable)	X	6N
Patient's Date of Birth	X	6N
Sex		1X

MEDICARE PATIENT INFORMATION

Medicare Provider Number	X	6X
Medicare Health Insurance Claim Number	X	12X
Medicare Part A Number of Covered Days		3N
Medicare Part A Covered Extension		5N.2N
Medicare Part A Coinsurance Number of Days		4N
Medicare Part A Coinsurance Amount Charged		5N.2N
Medicare Non-Covered Days		4N
Patient Responsibility		5N.2N
Medicare Amount Reimbursed		5N.2N

BLUE CROSS PATIENT INFORMATION

Blue Cross Provider Number	X	9N
Blue Cross Claim Certificate Identification Number (1)	X	15X
Blue Cross Plan Number (1)		3X
Blue Cross Claim Certificate Identification Number (2)	X	15X
Blue Cross Plan Number (2)		3X
Blue Cross Full (Rate 1) Day		2N
Blue Cross Full (Rate 2) Day		2N
Blue Cross Non-Covered Days		2N
Blue Cross Billed Paid		5N.2N
Blue Cross Patient Responsibility		5N.2N

COMMERCIAL PATIENT INFORMATION

No Fault/Worker's Compensation		1X
Commercial Policy Number	X	15X

COMMERCIAL PATIENT INFORMATION (cont'd.)

	DENIABLE	FORMAT
Commercial Insurance Company Name		20X
Commercial Room and Board		3N
Commercial Room and Board Rate		3N.2N
Commercial Room and Board Extension		5N.2N
Commercial Ancillary Days		2N
Commercial Ancillary Extension		5N.2N
Commercial All Inclusive Days		2N
Commercial All Inclusive Days Extension		5N.2N
Commercial Non-Covered Days		2N
Billed/Paid (Commercial)		5N.2N
Commercial Patient Responsibility		5N.2N

MEDICAID PATIENT INFORMATION

Provider Identification Number	X	8N
Locator Code		2N
Recipient Identification Number	X	11X
Agency (Medicaid)		2N
Rate Code (Medicaid)		4N
Special Program/Social Services Code (6)		6X
Recurring Monthly		5N.2N
Days at Posted Charges		2N
Posted Charges Amount		5N.2N
Resubmission Adjustment/Void Code		1X
Original Claim Reference Number		14X
Medicaid Only Number of Full Days		2N
Rate (Medicaid		3N.2N
Medicaid Full Days Extension		5N.2N
Medicaid Other (Include Part B)		5N.2N
Patient Participation		5N.2N
Medicaid Non-Covered Days		2N
Billed (Net Medicaid Claim		5N.2N
Prior Third Party		5N.2N

ITEMIZED CHARGE SECTION

	DENIABLE	FORMAT
Blood Pints Furnished		4N
Total Charge for Blood		5N.2N
Accommodation Days (5)		3N
Accommodation Rate (5)		3N.2N
Accommodation Code (5)		4N
Accommodation Total Charge (5)		5N.2N
Accommodation Non-Covered Charges (5)		5N.2N
Ancillary Service Codes (33)		3N
Ancillary Total Charge (33)		5N.2N
Ancillary Non-Covered Charges (33)		5N.2N
Total of Total Charge		5N.2N
Total of Non-Covered Charges		5N.2N

OTHER ELEMENTS

Discharge Date (Month and year only are non-deniable)	X	6N
Patient Discharge Status		2N
Statement Covers Period From/Through		12N
Accident Type Code		1N
Stay Approved Through		6N
Stay Denied Effective		6N
Carve Out Days		2N

DISCHARGE DATA ABSTRACT

	DENIABLE	FORMAT
Coding Method		1N
Medical Record Number	X	10X
Admitting Number	X	7X
Admit Date (Month and year only are non-deniable)	X	6N
Admit Hour		2N
Admit Status		1N
Age (At one year intervals for patients one year old or older; at one week intervals for patients less than one year old)		3N
Sex		1N
Race		1X
Zip Code		5X
Attending Physician License Number	X	8N
Operating Physician License Number	X	8N
Other Physician License Number	X	8N
Admitting Diagnosis Code		5X
Principal Diagnosis Code		5X
Principal Procedure Code		4X
Date of Principal Procedure	X	6N
Other Diagnosis Codes (4)		5X
Other Procedure Codes (4)		4X
Dates of Other Procedures (4)	X	6N
Admitting Source		1N
Primary Reimbursement		2N
Secondary Reimbursement		2N
Total Certified Days Used		3N

DISCHARGE DATA ABSTRACT (cont.)

	DENIABLE	FORMAT
Provider Identification Number	X	8N
Discharge Date (Month and year only are non-deniable)	X	6N
Discharge Hour		2N
Disposition		1N
Type Alternate Care Required		1N
Date Alternate Care Required		6N
Diagnostic Related Group		3N
Length of Stay		3N

NOTE: Any cell size containing fewer than six incidents is considered deniable; such groupings will either be eliminated or combined with another grouping.

Mr. SCHEUER. Ms. Quan, I think in last paragraph, page 6, first line, that $4 billion should be $4 million, should it not?

Ms. QUAN. Yes; I'm sorry.

Mr. SCHEUER. That is a typographical error.

Ms. QUAN. Yes.

Mr. SCHEUER. All right. We are going to recess now for about 45 minutes. We will be back here at 10:45—with our repeated apologies for this imposition on your time.

[Short recess.]

Mr. SCHEUER. We will recommence the hearing just as soon as Congressman Brown gets here.

Ms. Quan, why don't you come up to the table, and as soon as Congressman Brown gets here, we will ask you some questions. We will continue until 12:30, so we will make up half the time that we missed, or a third of the time that we missed.

The subcommittee will recommence its activities.

Ms. Quan, we are going to ask you a few questions. I have just one or two questions, Ms. Quan. On page 5 in the list of the purposes for which data may be used, you mentioned surveillance. Can I ask you, surveillance over what?

Ms. QUAN. This basically refers to utilization review studies, where we monitor length of stays in hospitals, whether appropriate ancillaries are being provided to patients—the sort of thing that really looks at the kinds of services that are provided to patients in facilities.

Mr. SCHEUER. I didn't get that last.

Ms. QUAN. The kinds of services that are provided to patients. We do pick up information on the actual ancillary services that are provided to patients on each bill.

Mr. SCHEUER. Do you carry on any surveillance of the diagnosis of the patient's needs, their illness?

Ms. QUAN. That is possible. In fact, that was part of the purpose of providing that information to the PSRO's, the professional standards and review organizations, so that they could match the diagnostic type, because we do pick up diagnoses in surgical procedures through the types of ancillaries that are provided to the patients and whether appropriate surgical procedures were used.

Mr. SCHEUER. We heard a great deal of testimony yesterday that a comprehensive health information system could provide instant diagnostic support to the physician at the time he was making his diagnosis, and bring together millions or billions of isolated bits of information that would be appropriate for that diagnosis. Would this kind of diagnostic assistance to the doctor at the time he was making the diagnosis be available through your SPARCS program?

Ms. QUAN. I suspect that that system—I am not familair with it—may be of a type that has more clinical information than this one. We are more concerned with demographic characteristics in the kind of information that resides in SPARCS.

Mr. SCHEUER. Would you say the system you have is mostly for purposes of accounting and control, and for rationalizing costs?

Ms. QUAN. Yes, I think so, although we have had a number of requests from epidemiologists to look at incidences of disease.

Mr. SCHEUER. But I take it there is no computer printout that a physician could get after he plugged in all the bits and pieces of information that he knew about the patient that would assist him in diagnosis? In other words, it doesn't assist in improving the quality of patient care at the time that care is being prescribed?

Ms. QUAN. At the time? No, it is not an instantaneous retrieval. It is basically a retrospective review——

Mr. SCHEUER. Right.

Ms. QUAN [continuing]. Of aggregate resources that are provided.

Mr. SCHEUER. Yes.

Would it review the quality of the diagnosis and the treatment of the patient as to whether in hindsight that was the appropriate diagnosis and the appropriate plan of treatment?

Ms. QUAN. I think all it can do is provide kind of a gross flagging system. You would look at indicators such as an appropriate length of stay for this patient. Do the ancillary costs appear too high or too low for this kind of diagnosis? And then you would have to go in and do a medical audit for more detailed information, and this system would not provide that kind of detail.

Mr. SCHEUER. And the penultimate line, the next to the last line of page 5, you talk about "Deniable data requests of those asking for specific data elements which might enable one to identify individual or institution."

Does an institution have any right to privacy?

Ms. QUAN. There was much controversy about that, and the Hospital Association felt that it might be unfair to the institutions themselves for that kind of information sometimes to be released.

Mr. SCHEUER. What kind of information?

Ms. QUAN. Any kind. They were very nonspecific. I have to tell you that we decided just to err on the side of being conservative in this respect; that is, we always come up with exceptions. For instance, for a small hospital in a rural area, picked up bits of information in and of itself or combination might enable you to identify a particular patient or a physician in his practices—by use of just the institution itself, because we do have 25-bed facilities in Upstate New York.

Mr. SCHEUER. I don't understand. What reservations could an institution have about being identified? What legitimate interest would they have to privacy as an institution?

Ms. QUAN. I don't feel too strongly about this one as being a deniable data element myself, and they just felt that information might be used against them.

Mr. SCHEUER. To help improve the quality of patient care perhaps?

Ms. QUAN. This is one I can't defend too well myself.

Mr. SCHEUER. Or provide care at a lesser cost?

Ms. QUAN. They feel morbidity statistics, mortality statistics might be used against them in the wrong kind of context without an informed framework about understanding those kinds of statistics.

Mr. SCHEUER. I think they would be entitled to an informed framework, of course. I am not quite sure in my own mind how they can justify withholding this data element.

Ms. QUAN. There was so much controversy about every data element, this is one that the State conceded. That information, by the way, has never been withheld in any of the requests, and for the State this is not a deniable data element. The State has a passthrough on hospital ID.

Mr. **Scheuer**. So they are required?

Ms. **Quan**. To provide that to the State, yes.

Mr. **Scheuer**. Because we are running very much behind time, and I apologize for the length of time that we recessed.

Congressman Brown.

Mr. **Brown**. Ms. Quan, your statement that certain types of institutional statistics might be regarded as highly private because they could be used against them reminds me of a recent event in my district in which 24 elderly patients of a local community hospital died under mysterious circumstances, and an investigation was conducted. The circumstances or the initiation of the investigation began entirely from an analysis of the high rate of deaths in this particular hospital, in this particular class of patients. I presume this is the kind of data that hospitals would feel a little sensitive about releasing if it were available to unauthorized users?

Ms. **Quan**. I suspect that is right, and that is also the reason why the State insisted that hospitals provide an ID number to be completely releasable to the State for our surveillance purposes.

Mr. **Brown**. Basically what we are trying to do is to get a general feel for this large area which none of us are very expert in. Do I understand that there are basically two types of health information systems, one that you might describe as basically an administrative system, and one that you might describe as an in-hospital clinical kind of a system? Are these the two general kinds of information systems that we have before us?

Ms. **Quan**. It sounded as though you might have heard about clinical information systems yesterday.

Mr. **Brown**. Yes.

Ms. **Quan**. And this one provides less detailed information but I believe serves the purposes of most of those kinds of monitoring and planning groups that we have been working with.

Mr. **Brown**. You say that the SPARCS system receives, stores and processes inpatient data from all hospitals in New York State. This is a very important and useful function, but this is not an online, real-time kind of information system, is it?

Ms. **Quan**. No, it is not. It is not meant to replace, either, any of the hospital information systems that should be there.

Mr. **Brown**. Correct, yes. I find that your description is extremely useful to us, Ms. Quan, and I would like to ask more questions, but in light of our time constraints I will defer any additional questions at this point.

Mr. **Scheuer**. I would like to echo Congressman Brown's comments about the quality of your testimony. It was a highly professional piece of work, Ms. Quan, and we are very grateful to you.

Mr. Skeen of New Mexico.

Mr. **Skeen**. Thank you, Mr. Chairman.

I am not going to take up a lot of time either. I just want to compliment you. I wasn't fortunate enough to be here earlier when you gave your presentation, but I read the material. One question I would like to ask. The cost estimate is $4 million?

Ms. **Quan**. $4 million.

Mr. **Skeen**. Have you been able to project any kind of saving figure to the consumers or to the systems?

Ms. **Quan**. That is the figure that we have put out, and it was very hard for us to do a cost-benefit analysis, the reason being that this form replaces a number of forms that are out there now. No cost analysis had been done of the forms that were in existence before, and there is a listing in the attachment of dozens of forms that the system now replaces.

Second, we know for a fact that there are numerous studies that are done every year by researchers and other health care organizations where they come in and they gather the same information time and again from the hospitals. Instead, what they are doing now is coming to SPARCS, which collects it once for all those users. We have had 55 requests to date, so it is difficult to exactly calculate the tradeoffs.

Mr. **Skeen**. Thank you very much. Thank you, Mr. Chairman.

Mr. **Scheuer**. Thank you very, very much, Ms. Quan. We are very grateful to you for your excellent testimony.

Mr. **Scheuer**. Now we will hear Mr. Byron Stuckey, Vice President of Technicon Medical Information Systems.

Mr. Stuckey, we were supposed to have had Erica Drazen, Manager of the Health Care Unit of the Arthur D. Little Co., but she is not here, I take it. She was coming down from Boston, and it may be that in this foul weather her plane was delayed, so we will hear you now as scheduled. Your testimony will be printed in its entirety at this point in the record, and I would suggest that you take perhaps 8 or 10 minutes to speak to us informally and sum up your thoughts, and you might well react to anything that was said here yesterday, if you are familiar with what happened, or anything that Ms. Quan had to say, and I am sure we will all have some questions for you after that.

STATEMENT OF BYRON STUCKEY, VICE PRESIDENT, TECHNICON MEDICAL INFORMATION SYSTEMS

Mr. **Stuckey**. Thank you, Mr. Chairman. I will not read the testimony since you have already consented to insert it in toto.

I would like to summarize very briefly and I do not plan to take much time in that summary, to highlight the points that are made in the paper, but not to go into them in detail.

Let me thank you first for inviting Technicon, me as a representative of Technicon, to appear before you and testify in this establishment of a coordinated health information system. I am vice president of Technicon. I have only been there a short time, although I have been in the industry a long time. I am one of the early enterers of the medical/hospital information system business and have been in this business for about 15 years. I was president of a different company for a number of years and joined Technicon only a couple of years ago.

Technicon's interest is as a provider of medical information systems to hospitals throughout the Nation. We are particularly interested in seeing those hospitals gain the maximum benefit through their use, and so our viewpoint, our perspective, is in seeing wider utilization by hospitals of medical information systems, and any help that we can get for them in assuring a wider utilization.

Specifically in this particular matter, we would like to share with you the information we have with respect to the gathering of the data, the issues that are involved in gathering of data for CHIS, and how the CHIS might use that data. The preparation of large volumes of data can be a very costly and prohibitive kind of thing to undertake.

There are a number of other impediments in the path of the potential establishment of a CHIS. One is the conflict of purposes between private and public requirements for such a system. Another is that there is hardly any standardization of medical data, clinical data.

Ms. Quan has been discussing this morning principally financial and administrative data. Technicon's systems are more involved in medical clinical data, and we find that there is almost no standard for the format of such data within hospitals.

A third issue is that not many hospitals have systems of any kind, and particularly those kinds of systems which involve clinical and medical information are not widespread.

Another issue that you have already spoken to and that is very present in the mind of the public is the confidentiality issue of that kind of information. It becomes more important, I think, in everyone's mind when you talk about clinical or medical information, than when you talk about financial or demographic data.

Another problem, of course, is the multitude of users that would propose to use a CHIS, both public and private, and how you get the needs made common and agreed upon between the public and private users. How do you pay for the gathering of this data and its processing when so many different and diverse users are probably going to be involved in its use.

In the paper that I have offered you that will later be published, I have suggested a strategy for overcoming some of these impediments, some specific recommendations about how to attack them.

First of all, it is important, I think, that you not require too much in the beginning, that you not attempt to define all of the elements of data that are to be included in a CHIS, but rather that you confine yourself to the more meaningful bits of data in the beginning, and test the utilization of such data to see how efficiently it can be gathered and processed and how much it can be used, protecting the flexibility to gather other data into the system as it is learned which data can best be utilized.

Again, few hospitals have systems. Those hospitals that do have systems are not complete in their clinical and medical aspects, and the ultimate should not be attempted in the beginning, because one certainty for failure, we have found, is to attempt too much in the beginning.

A second thing that we urge you to do is help us help the hospital community learn the ability for cost-effectiveness of information systems within their own institutions. Few have been studied. Even those that have been studied and have proved cost effective have not been accepted widely enough by the overall hospital community to receive the credibility required to have a great measure of installation activity.

A third thing that we would recommend to you is that reimbursement methodology be carefully reviewed to assure that the institution willing to improve its efficiency through installation of systems like this will get fully cost reimbursed, and in fact would recommend that you consider the possibility of penalizing those institutions who could improve their effectiveness, through installations of systems like these but elect not to do so.

The fourth item would be to bring together the public and private groups that are going to be involved in the utilization and benefits available through CHIS and let them help determine the requirements and the use to be made of such systems. Again, the paper itself that I have submitted to you has much more detail on each of these points, but in the interests of your time I have attempted to summarize just what the points are, so if you have questions regarding those points I would be happy to discuss those with you.

[The prepared statement of Mr. Stuckey follows:]

Statement
By
Byron Stuckey
Vice President, Technicon Medical
Information Systems Corporation

Before the
Subcommittees of Science Research and
Technology and on Natural Resources,
Agricultural Research and Environment
of the Committee of Science and Technology

United States House of Representatives

June 3, 1981

Mr. Chairman and Members of the Committee:

Thank you for inviting me to appear before your committee to discuss the need for, and implications of, establishing a Coordinated Health Information System (CHIS). In addition, I will address the issues that must be dealt with and the planning that should be completed before any such establishment could occur.

I am Byron Stuckey, Vice President of Technicon Medical Information Systems Corporation the developer of MATRIX, one of the first integrated, computerized medical information systems.

Technicon's particular interest and expertise concerning CHIS comes from our effort to maximize the benefits which a hospital can realize from Technicon's Medical Information System. Our medical information system, which is continually being enhanced, is one of the most sophisticated systems available today. Confidentiality of information has been assured in this system by the considerable design effort that has been expended. Hospitals which install Technicon's system gain the ability to improve productivity by speeding internal communications and automating much of internal data processing, as well as gaining the capacity to contribute a great deal of data toward the creation of a broad base of data for the analysis of health care delivery in the United States.

Issues and Problems

Preparation of the volume of data required for a CHIS exclusively for such purpose would be extremely costly — to the extent of prohibition. The process toward which we must aim is one in which health care providers collect data for submission to the CHIS as a byproduct of their normal activities. This data could be conveyed in a form immediately processable by the CHIS so that assembly of files into statistics would not require manual transcription or coding. Realizing this potential will take time and effort and the application of considerable expertise. In our view, the potential is now available in the form of know-how. Realization of this potential in this way will make the cost of both acquisition of the data by hospitals, and its processing by a CHIS affordable.

There are a number of impediments to establishing such a CHIS. The first of these is the potential of conflict of purposes. An institution acquiring an information system does so to principally improve its own internal operations. It has been estimated that between 25 percent and 40 percent of a hospital's expenses relate directly to information processing.

Efficient information systems are designed to improve the effectiveness and efficiency of this function. There are significant differences between systems developed to meet the private objective of operating a health facility efficiently and those designed to meet the public objective of obtaining data for determining how the nation's medical care should be deliver[illegible] Private organizations should not be expected to expend their funds to incorporate in their systems the capacity to provide data that may possibly contribute to the public interest, but has not even been suggested to be desirable. As things now stand, data that might easily and relatively inexpensively be made available as a base for a CHIS —through Technicon's or other advanced medical information systems — are not necessarily available. An incentive must be created for the private institutions to provide the data to meet the public objective.

A second impediment is the small number of hospitals which use computer systems, and the small use made of such computers. While over 70% of community hospitals use computers for financial systems, 30% do not use them for any purpose. Even in the limited use made by those hospitals which do, there is great variation in the format of the records processed. A CHIS to be capable of analyzing the data, must have essentially uniform data. While Medicare requires the reporting of a substantial amount of financial information for its cost reimbursement purposes and one might think that the needed kinds of data are therefore available in a comparable form, such is not the case. There are differences in the way that the various hospitals prepare their Medicare cost reports. The Department of Health and Human Services has been spending considerable effort trying to establish what they call an Annual Hospital Report, which is essentially a more uniform report of hospital finances than has previously been available. This report has become enmeshed in a debate concerning the administrative cost and burden of preparing the report and the effect of the new approach on the level of Medicare reimbursement for hospital services. Thus, solution of the problem of developing a coordinated hospital financial information system has not proven easy. This seems to be because the use of a coordinated system for regulatory purposes raises far more controversial issues than its use for research purposes. One of the issues with which you must deal is should the CHIS be designed to meet both these purposes or only the latter.

A third impediment to the creation of a successful CHIS is that less than a hundred hospitals have installed a medical information system with a substantial medical record data base. Even in many of these systems, the clinical data incorporated into the system is incomplete. Yet this may be the most important data. While the number of hospitals with such systems has had a sharply rising growth curve, beginning with eight hospitals in 1965, the rate of growth does not suggest that anything like a majority will have systems in place in the next several years.

A fourth impediment is the need to protect the patient, the physician, and the hospital from invasion of privacy by electronic access to medical data. Third party access to sensitive or confidential information is a very controversial policy area and one to which the Congress has spoken in statutes protecting the confidentiality of medical and proprietary information.

A fifth impediment to progress is the presence of a multitude of potential public and private users of a CHIS, with different needs and goals. The task of establishing a composite set of requirements and of establishing a system for sharing its costs is considerable. Experience with a number of industry-wide efforts to develop a uniform hospital bill is but one example of the challenge of integrating the information needs of a large number of users.

Strategy of Progress

A strategy for progress toward a CHIS that will overcome the array of impediments cited should be developed from the point of view of both those who will be expected to supply the input data and those who will use it. There are a number of steps that can be taken to increase the capacity of health services providers to deliver the needed input efficiently and inexpensively. These steps are based upon the providers' applying information systems to managing both their administrative and patient care functions, and thus making the provision of input to the CHIS a byproduct operation. Do not set your sights too high initially. 1. Not many hospitals have comprehensive medical information systems. 2. Even those systems which are considered comprehensive are not complete in the base of data accumulated. 3. Any attempt to define every bit of data to be ultimately desirable in a CHIS will greatly reduce the probability of success of the undertaking. It does not appear that every hospital, let alone other providers, will have, in the near future, the capacity to provide input to a CHIS as a byproduct of other activities. Many of the functions of a CHIS do not depend on surveying the universe of providers of health care. A valid sample will suffice. Planning Strategy should provide, as one element, to provide the capacity to deliver the required data. Likewise the data to be included in the sample should be selected from that data which is most widely available from providers. Finally, the initial definition of data required should be limited to that which is most widely available and is also most useful, protecting the flexibility to add elements to the data base for the CHIS, even as such flexibility is provided in Technicon's MIS Systems.

Second, while an increasing number of hospitals have concluded that the installation of a medical information system would advance their own efficiencies, and some hospitals that have installed systems have been evaluated in such a way that cost reduction and efficiency improvement have been clearly identified and measured, not enough such studies have been carried out in diverse institutions to reach a high level of acceptance. A government investment in research that could result in lowering the cost of health care would appear to be in the government's own interest — since it funds about 40 percent of the hospital services provided in the United State — as well as in the interest of the public at large.

Third, hospital reimbursement procedures should be modified to assure hospitals that install cost-effective information processing systems that their full costs will be covered. Furthermore, institutions whose efficiency is low because they fail to install information systems that would make them more cost-effective should suffer penalties. Careful investigation should be made of ways to help support shared system arrangements that would make it possible to assure smaller institutions of cost-effectiveness of applying sophisticated information-handling approaches to their operations. "Shared Systems" as used here is not limited to hardware systems but is inclusive of software systems sharing, also. Moreover, the reimbursement process will have to recognize that including information elements in a hospital's system that are intended not for internal use but for incorporation into a CHIS involves additional costs that must be born by the third party payors or some public organization.

Fourth, potential private and public users of a CHIS need to be brought together to jointly develop a list of requirements that they believe should be met and to begin exploring the methods that may be used to meet these needs. The discussions should be designed to establish the studies of methods that would be applied and the cost for doing so. They should also seek to determine what financing method is feasible and how costs may be shared among various government and private parties. What will be done depends largely upon the willingness of those who want to obtain the results to pay the costs.

Mr. Chairman, while I have described some serious impediments to the establishment of a CHIS and the agenda I have proposed for dealing with the problems will not be easy to complete, the potential rewards are tremendous and the direction seems inevitable. It is time we should get on with the task.

Thank you.

Technicon Medical Information Systems Corp

June 5, 1981

The Honorable James H. Scheuer
U.S. House of Representatives
Suite 2321 Rayburn House Office Building
Washington, D.C. 20515

Dear Congressman Scheuer:

During my testimony before your Subcommittee on June 3, 1981, it was requested that I provide to you a list of hospitals or medical information systems installed and which hospitals would be candidates for further study of the effectiveness of such systems.

Attached is a list of thirty (30) hospitals meeting this criteria. The seventeen (17) hospitals have Technicon systems include the name of the individuals within the hospital with whom contact should be made. Some of the hospitals listed which have National Data Communications Inc.'s system also list the individual to contact since I happen to have this information. Those hospitals having other vendors systems do not list a contact person with one exception. This name is furnished again since I happen to know this individual.

I am sure you will be interested to know that I learned after giving my testimony that a physician in New York University Medical Center desires to carry out a study of the impact of Technicon's system in that hospital on the work environment. Unfortunately this physician has recently lost his funding for this activity and is seeking additional funds. I have suggested that this physician make direct contact with yourself to explain his desires.

Sincerely,

Byron Stuckey
Vice President of Business Development & Long Range Planning

BS:emd
Attachment

6011 Executive Boulevard, Suite 214, Rockville, Maryland 20852 (301) 770-1620

Technicon Medical Information Systems Corp.

El Camino Community Hospital 2500 Grant Road Mountain View, CA 94040 Mr. Bruce Tilley Director, Management Engineering	464 Beds	Operational Heavy direct physician usage
Ralph K. Davies Medical Center Castro & Duboce Streets San Francisco, CA 94114 Mr. Jack Hauser Vice President for Administration	290 Beds	Operational Heavy direct physician usage
Nebraska Methodist Hospital 8303 Dodge Street Omaha, NB 68114 Mr. Clark Mathisen Vice President	404 Beds	Operational System self installed
Maine Medical Center 22 Bramhall Street Portland, ME 04102 Mr. Donald McDowell Vice President and Treasurer	328 Beds	Operational Heavy direct physician usage
National Institutes of Health NIH Clinical Center 9000 Rockville Pike Bethesda, MD 20014 Thomas Lewis, M.D., Chief	541 Beds	Operational All entry of orders directly by physicians
Methodist Hospital of Indiana 1604 North Capitol Indianapolis, IN 46202 Mr. Zed E. Day, III Director of Computer Services	1,075 Beds	Operational Heavy direct physician usage

Medical College of Virginia P.O. Box 510, MCV Station Richmond, VA 23298 Mr. John Marsh, III Assistant Director of Institutional Systems	1,058 Beds	Installation nearing completion
The Jewish Hospital of St. Louis 216 South Kingshighway St. Louis, MO 63178 Mr. George Bridgemon Vice President	600 Beds	Operational Heavy direct physician usage
Strong Memorial Hospital 601 Elmwood Avenue Box 698 Rochester, NY 14642 Ms. Ann Stunden Data Processing	717 Beds	Operational Heavy direct physician usage
Saint John Regional Hospital P.O. Box 2100 Saint John, NB Canada E2L 4L2 Mr. David Shaw Director of Finance & Information Services	482 Beds	Installed, in process of bringing all nursing stations into operations.
University of Illinois Hospital P.O. Box 6998 Chicago, IL 60680 Mr. Allan Baldwin Director, HIS	710 Beds	Operational Bringing nursing stations into operations
New York University Medical Center Hospital Administration Room HW-285A 560 First Avenue New York, NY 10016 Ms. Patsy Marr Director, HIS	883 Beds	Operational Bringing nursing stations into operations

St. Francis General Hospital 45th Street off Penn Avenue Pittsburgh, PA 15201 Mr. Robert Provost Director of Finance	750 Beds	Installation in process
Waukesha Memorial Hospital 725 American Avenue Waukesha, WI 53186 Mr. Jack Cleary Director, Data Processing	405 Beds	Operational Bringing nursing stations into operation
City of Faith, ORU P.O. Box 36000 Tulsa, OK 74171 Mr. William Luttrell Chief Administrative Officer	777 Beds	Admission, Tranfer and Discharge of Clinic Outpatients operational
Kenosha Memorial Hospital 6308 Eighth Avenue Kenosha, WI 53140 Mr. John C. McGinty, Jr. President	315 Beds	In process of installation

National Data Communications, Inc.

Baptist Hospital of South East Texas College & 11th Streets Drawer 1591 Beaumont, TX 77704 Guy H. Dalrymple President	369 Beds	Operational
Huntington Memorial Hospital 100 Congress Street Pasadena, CA 91105 W. Kevin Hegarty President & Chief Executive Officer	504 Beds	Operational
Baylor University Medical Center 3500 Gaston Avenue Dallas, TX 75246 Boone Powell, Jr. President	1,125 Beds	Operational
Deaconess Hospital 600 Mary Street Evansville, IN 47747 David A. Johnson Executive Director	509 Beds	Installed
Lakeland General Hospital Lakeland Hills Blvd. Draswer 448 Lakeland, FLA 33802 Sherwood D. Smith Executive Director	616 Beds	Installed
Bethesda Memorial Hospital 2815 S. Seacrest Blvd. Boynton Beach, FLA 33435 Russell T. Clayton Administrator	259 Beds	Installed

National Data Communications, Inc.

Children's Hospital of Michigan 3901 Beaubien Detroit, Michigan 48201 Robert H. Gregg, MD President	268 Beds	Installed
South Community Hospital 1001 S.W. 44th Oklahoma City, OK 73109 Dan E. Tipton President	392 Beds	Installation in process

DATACARE

Roanoke Memorial Hospital Belleview at Jefferson Street Box 13367 Roanoke, VA 24033 William H. Flannagan President	675 Beds	Operational
University & Hospital Clinic University of Nebraska 42nd Street & Dewey Avenue Omaha, NE 68105 Robert J. Baker Director	258 Beds	Operational
Denver General Hospital W. Eighth Avenue & Cherokee Denver, Colorado 80204 Abraham Kauvar, MD Manager	353 Beds	Installing

DATACARE

Columbia Hospital 2025 E. Newport Avenue Milwaukee, Wisconsin 53211 Paul W. Kempe, President	406 Beds	Installing
Fairfax Hospital Association 8011 Braddock Road Fairfax, VA 22151 Franklin P. Lams Executive Vice President	850 Beds	Operational

IBM's PCS

Parkland Hospital 5201 Harry Hines Blvd. Dallas, TX 75235 Tom Noble, President	780 Beds	Operational Limited applications
Duke University Hospital Durham, NC 27710 Richard H. Peck Administrative Director	895 Beds	Installed

Mr. SCHEUER. Very good. Congressman Brown.

Mr. BROWN. Thank you very much.

Mr. Stuckey, I have read your paper over fairly carefully, and I am impressed with the recommendations that you make. I gather that you feel that Technicon, and I presume perhaps other suppliers as well, can meet the technical requirements for safeguarding privacy in a clinical or other health information system. You have worked on that problem considerably?

Mr. STUCKEY. Yes, sir. We have done so in the environment of the single institution and the protection of the medical information within that institution. We have not done so, obviously, in the broader environment that you are considering in the coordinated health community program. The issues are slightly different. The issues in the medical information system within a hospital are to provide access to those who need it, while at the same time prevent access by those who don't need it. The issues in fact, are the same in the broader context, but the methyodology, the technical methodology for protection I suspect would be somewhat different. But we have dealt with those issues because they are very important issues in the single hospital environment.

Mr. BROWN. You don't think they are insolvable, then?

Mr. STUCKEY. No, absolutely not.

Mr. BROWN. You also referred to the problems involved in the standardization of data needs, and so forth, in the clinical system, this being a largely unstandardized field at the present time. Yet I seem to be aware, and I will ask you if you are not aware, of clinical systems established in hospitals which have made an effort to solve that problem. In other words, is this not a problem which, though very large, if properly addressed is subject to the same type of solutions that other standardization problems are?

Mr. STUCKEY. Yes. I think the difficulty is enlarged with respect to this data merely because there is so much of it. There is such a broad scope to the medical clinical information that I think one must take great care that each part of the data is defined as an element, and identified as such, so that it can be standardized in format. But, again, as you said, if you recognize the problem, and that is our purpose really in highlighting the problem, it can be dealt with, has been successfully dealt with, in individual hospitals.

Mr. BROWN. Now the missing witness, Erica Drazen, who didn't show up, in her paper referred to her experience with the TRIMIS system and the development of what might almost be considered a prototype of a medical or health information system in the Department of Defense. I don't know what the status of that system is, and I hope we will get testimony on that later, but it bears on another recommendation that you made.

Apparently that system in the DOD went through a number of startup problems, which I gather, and I am a little hazy on this, stem from its effort to be too all-encompassing, too complete in the initial design phase. You recommend that any large system be developed incrementally without attempting to define all of the elements completely at the beginning, and I relate the two to each other, since apparently, at least at one stage, the TRIMIS may have attempted to do what you are recommending not be done: that is, take off too big at the beginning.

Are you familiar with this situation?

Mr. **Stuckey**. Yes, I am quite familiar with the TRIMIS thing. My company is involved today in the preparation of a response to a TRIMIS request for proposal which came from a congressional mandate that they acquire three commercially available systems in order to test, if you will, or to demonstrate, the viability of such systems, so we are deeply enmeshed in the response to that request at this moment.

Mr. **Brown**. As I recall, it was the Government Operations Committee, or a subcommittee of it, that went into and investigated this fairly thoroughly. We have walls between subcommittes here so I don't know exactly what they did.

Mr. **Stuckey**. I understand.

I was discussing with a colleague a little while ago at this moment because as I understand what the congressional mandate was, it has not been carried out clearly and fully. The mandate, as I understood it, from my perception, was to acquire systems that were commercially available—off the shelf. I think, in fact, those were the words. What the group that put out a request for a proposal has done is very common, in that they looked at commercially available systems. They then described a composite of those systems for acquisition, none of which systems can meet all of the requirements. Everyone, including ourselves, will have to expend substantial funds to meet the requirements of the RFP. Therefore, we can't offer our commercial off-the-shelf system in response to the RFP, but that is not uncommon. It is a typical situation.

Mr. **Brown**. It is not uncommon for congressional committees or the Congress to have its clearly expressed mandate disregarded, or honored in the breach, as you might say, and that is not necessarily intended as a massive criticism, because frequently the Congress can be wrong, but there ought to be some way of reconciling these things.

Mr. **Stuckey**. Yes, but back to your basic question. The TRIMIS program, which I have followed with some interest from afar for many years, did set out, it seemed from my perspective, to attempt to engineer an ideal all-encompassing system before they undertook any development. And as is often the case, it was engineered to death and nothing ever came of it.

Each passing day you learn a new requirement that you didn't know the day before, and you try to incorporate that requirement along with the requirements you already knew, and you never get to the design point such that you say "I have now finished the design and I am ready to undertake development." And that is, from my view, what happened with the TRIMIS program.

Mr. **Brown**. In our own subcommittee activities here, we, in addition to trying to educate ourselves and understand the problems in this area, are also interested in what constructive steps might be taken at the governmental level or the congressional level. You have commented that you feel that R. & D. investment by the Government in the development and improvement of these systems is a useful function of Government that probably wouldn't be performed otherwise, since the units of the industry, generally speaking, are highly fragmented and probably could not conduct an overall research program suitable to meeting the needs for a comprehensive system on their own initiative. Would you care to elaborate on that briefly?

Mr. **Stuckey**. Yes, thank you, I would. NCHSR—are those initials familiar to you?

Mr. **Brown**. The National Center for Health services research.

Mr. **Stuckey**. Right—funded some studies that were carried out over a lengthy period at our installation, El Camino Hospital in northern California. Three and a half to five years was the period over which these studies were carried out, to prove the cost effectiveness of the Technicon Medical Information System in that institution. At the same time, El Camino Hospital, through its own industrial engineering staff, did parallel studies. These studies proved to our satisfaction, to the hospital's satisfaction, the ultimate net cost savings of such a system, that is to say, that after payment of all expenses of the system and its operation, they lowered the cost of the delivery of patient care within the hospital, and separate and apart and in addition to that, they improved the quality of care delivered at El Camino Hospital.

Unfortuantely, one of the reactions to that series of studies and those reports is that El Camino does not represent the broad base of community hospitals in the United States. It is one of a kind. That is the argument you are going to get from any such study.

What we are urging is that we need some help in a broad-based application of such study methods that would prove the viability, the success of such systems in representative hospitals, more than one, so that the credibility of such information would be more widely accepted than it has been in the past.

I have been in this business, as I mentioned, 15 years, and each of those years we have all been confident that this is the year that hospitals will recognize the need for these kinds of systems and begin to implement them. That year may have come in 1981, but if it has, it is not yet apparent.

I mention in the paper that there are less than 100 hospitals in the United States that have comprehensive medical information systems installed. In fact, the number, if you really get to comprehensive systems, is probably 30, a very, very small number.

As you talk about a coordinated health information system, one which could utilize the kind of data that is a byproduct of a medical information system, it seems to us that it would be very beneficial if you had a wide base of hospitals with such systems installed, so that the cost of producing the data to the CHIS would be almost irrelevant, because it would be a byproduct of other activities. Not only the collection of that data but the furnishment to the CHIS in a form that would be processable without any further coding or transcription. It would be a very, very advantageous thing to have.

Unfortunately, we don't see any indications that in the next few years that is going to be available, and you could spend an awful lot of money preparing data for a CHIS that could be a natural byproduct of a cost-effective system. So our urging is apparent, and it is our perspective, we admit it. We would like some help in getting more MIS systems installed in hospitals, so that this information would be available as a byproduct to a thing like CHIS. We are frustrated in our ability to get acceptance of the information that is available that proves that these systems are cost effective and that they improve the delivery of patient care.

Mr. Brown. Other witnesses have commented and in fact documented the fact that there has been inadequate research into the cost effectiveness of such systems, and this is inherently a very mushy field.

Mr. Stuckey. Yes.

Mr. Brown. The elements are very hard to define. The evidence is, to some degree anecdotal, instead of as hard as we would like, and I would concur with you that it would be extremely important to improve this particular type of information.

Let me ask just one additional question. Yesterday we had a very dynamic and charismatic witness who indicated that the next step toward progress in this important field in terms of just what you are describing of a rapid maturing of the national capability, would be to bring together a partnership of public and private users, policymakers, in order to begin the process of solving the problems, or the obstacles, meeting the obstacles here.

You have made somewhat the same point in your statement, where you say:

> For protection, private and public users need to be brought together to jointly develop a list of requirements that they believe should be met, and to begin to explore the methods that may be used to meet these needs.

The question is, are we ready to do this now, and is there a role for the Federal Government in giving leadership to this process, so that it could be brought about in a timely fashion?

Mr. Stuckey. I think the answer to both questions is yes. The early planning for this sort of thing with the involvement of the people who will have to carry it out, namely, again, the private and public groups that will be involved, is extremely important for two reasons: One is to get their participation, their active involvement, and their acceptance of it; second, to assure that in fact they carry out the activities that we are undertaking. So I think it is time. We didn't do, from my perspective, a very good job 15 years ago in planning for medical information systems, and that is why we are facing the slow maturity of the market today. That is one of the reasons. And we would like to avoid that in something like a CHIS, and I think the Federal Government has a definite role to play.

Unfortunately, our own feeling is the Federal Government's role in proliferation of medical information systems has been mostly negative. The cost reimbursement approach that has had such a great effect today is one of the greatest detriments to selling systems. Each hospital that we sell a system to must go through a health services agency approval, which is a function of Public Law 93-641. They feel a negative impact of having to go through this special procedure to get approval to prove that the system that they are about to install will be good for them.

Of course, what we would like to see is a reversal, where the Federal agency says, "We want you to put in these things to help deliver care in a more cost-effective way."

I am not sure we will ever get that great a transition, but we would certainly like to move in that direction. CHIS's are similar in that respect.

Mr. **Brown**. I thoroughly concur in your views as to the proper role of the HSA's in this regard, and I would like to encourage that myself. If you have any idea about how we might do that, please let us know. Thank you very much for your testimony.

Mr. **Stuckey**. Thank you, sir.

Mr. **Scheuer**. Congressman Walgren and cochairman of this hearing.

Mr. **Walgren**. Just briefly. Thinking of the HSA's and their role in this, if they were interested in this kind of thing, it would broaden the market for a system?

Mr. **Stuckey**. Absolutely.

Mr. **Walgren**. Quite rapidly, I would think?

Mr. **Stuckey**. Absolutely.

Mr. **Walgren**. So there must be some way that, if it can be demonstrated that it is cost effective, to interest them, and then the HSA's might just be your best ally?

Mr. **Stuckey**. One of the deep problems, Mr. Walgren, is the idea of cost reimbursement. There is almost no incentive, in fact, for hospitals to reduce the cost of patient care delivery when they are reimbursed upon cost. There are many advocates who feel that a basic revision in that philosophy needs to occur, so that hospitals are paid for effective delivery.

The diagnosis-related groupings that are being tested in New York and New Jersey are perhaps an answer to this question, where you pay a hospital an amount for providing care in a certain diagnosis, so that if the hospital does it more efficiently, it can profit from having done it more efficiently.

But as long as you are going to reimburse them whatever their costs are, there is absolutely no incentive to reduce those costs, and the disincentive with respect to information systems is that they are leery of the possibility that they might not be fully reimbursed the cost of those systems. They might be somehow excluded as the medicare reimbursement agencies often do exclude certain costs from the reimbursable base. So they are put on notice that certain aspects of their costs might not be included in the reimbursable cost base, No. 1, and, No. 2, even if it is, they will only be reimbursed for the cost, and there is no incentive for improvement in effectiveness. So it is a very basic problem in reimbursement methodology.

Mr. **Walgren**. How long ago was the El Camino Hospital study done?

Mr. **Stuckey**. The last, final report was in fact issued in June of last year, and that was the end of a 5-year period over which a number of different studies, components of studies and different reports were issued during the period. So you have to back up from last June for 5 years, and you would be in 1975 when they were first undertaken.

Mr. **Walgren**. Have the Federal financing people or the statistical people sponsored other studies around the country of this kind of thing?

Mr. **Stuckey**. They offered in that particular case to study more institutions than the one. My guess, my speculation, is that no one came forward with other hospitals to study, because the resultant work was in the one hospital, El Camino. One of the problems, of course, in 1975 is the very small number of such systems were installed. As I have already said to you, the truth of the matter today is there is still a very small number. While today there are probably 30 systems in hospitals throughout the country that could be studied, in 1975 there were probably 8, so there wasn't a wide selection of systems that might be studied, whereas today there is a bit wider availability of systems that are installed and in operation.

Mr. WALGREN. But you know of no other ongoing studies of those?

Mr. STUCKEY. No, I do not.

Mr. WALGREN. Thank you very much.

Mr. SCHEUER. You are saying that there are no case histories indicating success or failure for the 30 hospitals?

Mr. STUCKEY. No, I don't intend to say that, Mr. Scheuer. In fact, there are many, but, again, they are believed by other hospitals to be largely self-serving, and so they don't have the acceptance or the credibility that is necessary to make them meaningful from the standpoint of proliferation of these systems, and to some extent anyone would have to acknowledge they are that. They are self-serving. They are public relations activities, and that is another reason for the need for a third party like the Federal Government to participate in them, and to publish results, so that all can accept the results as credible and applicable to a broader base and universe of such activities.

Mr. SCHEUER. How would we get hold of whatever self-serving or not self-serving reports that do exist for these 30 hospitals? At least that would provide a starting point for us and we might either go to HHS or to the General Accounting Office or the Government Operations Committee, and then have them review these reports for their self-serving characteristics and actually study the institutions and then come up with some conclusions about each of these 30 institutions and some overall conclusions.

Mr. STUCKEY. The starting point, obviously, would be determination of the hospitals which are capable of study, who have systems that are complete enough, thorough enough and have been in operation long enough to give you a studyable base.

Mr. SCHEUER. Could you give us a list of them?

Mr. STUCKEY. Yes, I could certainly do that, and beyond that, to——

Mr. SCHEUER. And the person that we would be in contact with?

Mr. STUCKEY. Yes. Certainly as far as Technicon's installed base, and beyond that to some extent.

Mr. SCHEUER. You talk about the system being capable of rationalizing costs and also improving the quality of patient care. Is that quality of patient care improvement that you are talking about all retrospective, or do you give an improved diagnostic capability to the doctor at the time he is treating the patient in making his own diagnosis?

Mr. STUCKEY. Technicon's system is the only one, and again I have to remind you that I have only been at Technicon a short time, a couple of years, and prior to that time I was with a different company in this same business, Technicon's system is the only one that has had wide acceptance of direct use by the physician. El Camino Hospital is an example. The clinical center at the National Institutes of Health right here in Washington, uses the Technicon system. In that use of the system the physician himself, sitting at a CRT terminal, enters patient orders—orders for patient care into a Cathode ray tube, it is a display. In the Technicon system, he uses a light pen and what is widely stated to be a menu-selection process, and he actually enters all of his orders for patient care through the video display as opposed to writing them in the chart.

Now, when a physician uses this kind of system in this way, the system is able to respond to him in the immediate term with information helpful to him in both the diagnosis and treatment of the patient. It is able to do more than that, in that the information that needs to be conveyed to the physician about the course of care that is being delivered to the patient is available to him much earlier.

For example, when the physician orders something like a lab procedure, instead of the lab results taking an extra day to be available to the physician by delivery on a piece of paper into the patient chart, it is available to him much earlier through the automation of the system. Where the lab instrument itself, if it is automated, can be interfaced to the network then the actual lab results can be brought into the computer system much earlier than they could have been had human intervention taken place in several points in the conveyance of this information. So information is available to him more rapidly.

It is absolutely proven to be more accurate, because the human intervention points are removed, and each of these intervention points are just an extra opportunity to mistranscribe, to misrecord, to lose data, so many of those gaps are closed, and that is what brings it to him earlier. That is what makes it more accurate, and that is why the use of Technicon's system makes it one of the few systems that really can provide some help to the physician himself.

Now, the key point here is that there are many other systems which have the capability of use this way, but none have had the success that Technicon has had in getting the physician to actually sit down and enter orders into the terminal device.

Most such systems, for example, IBM's PCS system, which is at Duke University, uses a term that identifies to me the difference. They use a term called DTO, which means data terminal operator. They have at each terminal, each CRT terminal, a skilled typist, who enters orders.

Physicians don't use the terminal device; they write their orders and a typist enters the order, so you have removed the potential for interaction between the man and the machine, and this is a very critical area. It has been a very difficult area for Technicon. It is a difficult area for anyone.

I think Mr. Brown yesterday asked the question with respect to the man-machine interface, and it is a very critical area, and the reason is——

Mr. SCHEUER. Do doctors prefer dictating to a secretary or do they prefer punching it into a computer?

Mr. STUCKEY. Typically, physicians, like all of us, identify the use of a terminal device as a secretarial activity. It is a psychological thing as much as anything else. It is a real problem as well.

Physicians don't like to do things that they are not highly adept at doing, and secretaries are more adept at using terminals than physicians are. Physicians don't like, and you and I don't like, to be embarrassed because somebody else can use this thing better than we can, and that is a discouragement, so it has been a very real problem to get the physician to gain access to the real-time information that he can gain access to by use of the terminal device.

We have had pretty good success. We have had more success than most, but we have had limited success when you look at the universe of hospitals that could be utilizing such systems.

Mr. SCHEUER. Just to answer a question that we discussed with Ms. Quan, do you believe institutions have a right to privacy?

Mr. STUCKEY. I thought of that as Ms. Quan made her statement, because in my statement I make a similar comment with respect to confidentiality of data. In the broader sense, privacy of data from my perspective, institutions feel that they need to be protected from the availability of information about the institution and the practices occurring there from certain classes of people.

Mr. SCHEUER. What classes, newspaper reporters?

Mr. STUCKEY. That is one class.

Mr. SCHEUER. Government investigators?

Mr. STUCKEY. That is the more specific one.

Mr. SCHEUER. Irate consumer groups?

Mr. STUCKEY. Yes, hospitals have a horror——

Mr. SCHEUER. Business groups?

Mr. STUCKEY. That a litigationist, an attorney representing a plaintiff in a malpractice suit, could have access to their data base, and could use that data base to his advantage and to his client's advantage against them. So they are very, very sensitive to the idea of this information being readily available to someone who would be an opposing position to themselves.

Mr. SCHEUER. In an adversary position?

Mr. STUCKEY. Yes. So I think that is the broader use of the word "privacy." I don't think it is really the narrow use of the word privacy but, yes, I think hospitals are very sensitive to the requirement.

Mr. SCHEUER. Frank Lloyd Wright, the great American architect, said one time surgeons can bury their mistakes but we have to cover ours with ivy.

Now the question is, are we going to let them continue to bury their mistakes, without any kind of oversight or surveillance either in the public sector or in the nonprofit sector, citizen groups, or through our judicial system?

Mr. STUCKEY. There is an opposing very salient point of view in this respect. El Camino Hospital, the question was asked yesterday about malpractice insurance and whether or not such insurers would recognize the lowered risks of the availability of real-time information to the physician. El Camino Hospital formed its own insurance agency for its physicians in malpractice, and has saved a huge amount of money because they implemented in the system some risk-management programs such that if certain orders are entered and the computer system recognizes a potential conflict, it informs the physician.

Mr. SCHEUER. What do you mean by conflict, potential problem, potential risk to the patient?

Mr. STUCKEY. Potential problem, conflict in the order he is placing with the previous order that is being carried out. It tells him now, in response to the entry of that order, of that conflict, and gives him the additional data availability to make a better, more informed decision, and they have in fact lowered their malpractice coverage costs substantially through the use of the system in that way.

Mr. SCHEUER. We discussed this yesterday and nobody had any hard evidence, and this is the first time we had verified the fact that insurance companies will recognize the reduction of the risk to them of a doctor who has a computer assist in the diagnostic process.

Mr. STUCKEY. El Camino has done this, and of course they are very proud of it, and they are very proud to tell people about it.

Mr. SCHEUER. Who is the person whom we would be in contact out there?

Mr. STUCKEY. Ed Hawkins is the chief executive officer at El Camino, and I am sure he would be happy to share that information.

Mr. SCHEUER. Very good. Is there anything else?

Your testimony has been extremely helpful to us, Mr. Stuckey, and we thank you for it. We also thank you for your patience in waiting over the suspension when we were doing our work on the floor of the House. Thank you very, very much.

Mr. STUCKEY. Thank you.

Mr. SCHEUER. Has Erica Drazen arrived?

We will now go to our last witness, Mr. Allen J. Manzano, who is senior vice president of the American Hospital Association, I presume.

Would you come forward, and if you wish to bring Mr. Cleve Killingsworth along, by all means do that.

Mr. Manzano, we are running very late. We have approximately 15 or maybe 20 minutes at the outside. What we would like you to do, if it is satisfactory to you, is chat with us briefly for 6 or 8 minutes, and then perhaps another 10 or 15 minutes to ask questions.

STATEMENT OF ALLEN J. MANZANO, SR., VICE PRESIDENT, THE AMERICAN HOSPITAL ASSOCIATION, ACCOMPANIED BY CLEVE KILLINGSWORTH, DIRECTOR, DIVISION OF HOSPITAL DATA, AMERICAN HOSPITAL ASSOCIATION

Mr. MANZANO. Thank you. I have a statement which I think will take only about 2 minutes, which I think will get us to where you want to be. I am Al Manzano, senior vice president for the American Hospital Association, and on behalf of our 6,300 hospital institutional members I want to thank you for the opportunity to present our views on the question of how best to achieve a coordinated system for health information.

We want to assure your committee that we will be available and willing to work with you in furthering its exploration in the resolution of the problems which I am sure you are encountering in defining and developing such a system.

With me today is Mr. Cleve Killingsworth, who is the director of our hospital data center, and after a brief oral statement of our concerns and interests we will be prepared to respond to your questions as our statement may suggest them to you. We would request that our written statement, as submitted, be also placed in the record.

Mr. SCHEUER. It will be printed in its entirety at this point in the record.

Mr. MANZANO. The hospitals are a major source of data concerning the nature of the health delivery system, the patient, the kinds of treatment that the patient is provided and the organization and financing of health care. Hospitals see the function of data primarily as it relates to the care of its patients. Other uses of data are recognizably vitally important, and hospitals are more than willing to participate in reporting, collecting, manipulation and display of data as it may appropriately be required by such other functions, both within and outside of the hospital.

Hospitals understand the crucial importance of useful data and resulting information at community, State and national levels. The concept of a coordinated information system, we believe, is a workable one. Its development, however, must be tempered by pragmatic concerns for the utility of its products and its physical and social costs.

Our belief is that large scale federally based systems are probably ultimately impractical. Further, Federal centralized systems and/or controls will inevitably lead to conflicts with regional, communal and institutional goals and values. They are excessively difficult in terms of the requirements for the systems management, and they often conflict and lead to the deterioration of useful and valid private sector efforts. A system which is highly focused at the national level is by nature difficult to adjust, and inherently inflexible.

Past efforts to impose systems on a national scale have been, unfortunately, arbitrary, and probably never realistically achievable. They tend to ignore or deprecate other existing and experienced systems, and by the very fact of mandate, lead to the loss of essential cooperative sharing attitude on the part of participants.

Our own experience with the development of hospital data networks at the national level suggests that a diverse flexible, yet coordinated approach, can most successfully achieve the purposes of useful data and information, and assure their availability to all legitimate groups with the least conflict and costs.

We believe policy in a coordinated system must be multisector and evolutionary. We believe the collection of data must be based on its usefulness and value. We believe that the quality of such data depends more than anything on its usefulness to those who must collect it.

And lastly, that there must be full recognition of the differences in the data needed at the national, regional and local levels.

Mr. Chairman, we would be happy to respond to questions.

[The prepared statement of Mr. Manzano follows:]

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STATEMENT OF THE AMERICAN HOSPITAL ASSOCIATION
TO THE
SUBCOMMITTEES ON SCIENCE, RESEARCH AND TECHNOLOGY
AND
NATURAL RESOURCES, AGRICULTURE RESEARCH AND ENVIRONMENT
OF THE
HOUSE COMMITTEE ON SCIENCE AND TECHNOLOGY

June 3, 1981

The American Hospital Association, which represents over 6,300 member hospitals and other health care institutions, as well as more than 30,000 personal members, is pleased to have this opportunity to present its views on the subject of a coordinated health information system.

Our Association has long been committed to the implementation of well-planned, cost-effective health data systems to serve the needs of patients, health care professionals, institutions, third-party payers, and all levels of government. The AHA supports the use of such systems in helping to maintain the public's health. We are aware of the significant benefits to be obtained through the intelligent use of computer systems in hospitals and in the entire health care delivery system. In policy-making at all levels, reliable data are of critical importance, and coordinated data systems ensure comprehensiveness and avoid costly duplication of effort. The AHA encourages fact-based health care policy analysis and decision making, and we actively support the standardization of nomenclature and codes.

The AHA is very concerned, however, about the many problems and costs of large centralized information systems such as may be envisioned in a coordinated health information system (CHIS). We believe that effective coordination is not equivalent to centralization (especially in a system controlled by the federal government) and that comprehensiveness of data for its own sake is unnecessarily costly. Moreover, the AHA believes that any system must recognize the specific needs of its various users as well as the limitations of suppliers of data and their unique constraints. We have observed that below the federal level, health data systems are evolving according to state and local needs and believe that such developments lead to more efficient collection and effective use of data. Given this extensive private sector activity, we feel that the federal government's logical role would be one of filling gaps, where necessary, rather than one of being the controlling agency.

AHA INVOLVEMENT WITH INFORMATION SYSTEMS

The AHA has studied health care information systems over an extended period and has been involved in data collection activities which directly or indirectly support operations, policy-making, and research at the hospital, area, state and national levels. As a result of this involvement, the Association has developed criteria for evaluating health data systems which call for a review of:

(1) Capacity to meet user needs;

(2) Confidentiality protection;

(3) Appropriateness of application;

(4) Flexibility (users' ability to effect changes in a system);

(5) Adaptability (not imposing organizational and hardware requirements on suppliers and users of data); and

(6) Total cost

The application of these criteria are explained in a series of AHA Office of Public Policy Analysis policy briefs, the most recent of which is entitled "Integrated Data Management Systems--Description and Policy Concerns" dated March 10, 1981 (copies of which are attached).

AHA analysis has shown that the potential key disadvantages of a large, centralized comprehensive health data system include excessive costs, poor assessments of specific user's information needs, breaches of confidentiality, encouragement of low quality research, potentially excessive government regulation, the slowing of hospital cash flow, and the discouragement of competition for the collection of hospitals' data by private entrepreneurs. Other key policy concerns include the extent of voluntary hospital involvement and the extent to which relative costs must be borne by hospitals. An example demonstrating some of these concerns is reflected in the System for Hospital

Uniform Reporting and the Annual Hospital Report regulatory requirements that were proposed by the Department of Health and Human Services in the past few years but fortunately were not implemented.

SPECIFIC MAJOR ISSUES IDENTIFIED BY THE AHA

Structure

The AHA believes that there should not be a single hierarchical structure for a CHIS but, rather, an incremental development of existing systems with the ability to interface at appropriate levels with the federal government's role limited to that of filling gaps. It is unrealistic to expect any information system to address all conceivable needs for health care data in this country. Such a goal would require a massive data base, parts of which would be infrequently used, and the costs of ongoing data base maintenance would be enormous. Such a massive system, we believe, is unrealistic conceptually and financially.

Control

The AHA supports the continued pluralistic development of health data systems with decisions on data content made on a decentralized basis by local users and suppliers. Local problem-solving is essential to the optimum provision of health care services and is consistent with the emerging national philosophy of deregulation and decentralization of problem identification and problem solving. Concurrently across the nation, coalitions of health data users cooperate in various ways to address their mutual needs including, as an example, the use of AHA's own hospital Data Network which is publicly available.

Data Quality Control

In addressing the issue of data quality, there is a need to recognize the appropriate balance of data accuracy, comprehensiveness, timeliness, and cost. The basic elements of quality control in data systems are adequately trained personnel and the editing of data before they are included in a system. The AHA believes that competition among data systems provides incentives to raise the level of quality. It would be most difficult in a national system to control data quality if local suppliers and users perceived the system as not particularly relevant to their individual needs.

Access Control

At national, state, and local levels, choices of "brokers" for information systems should be based on the actual capabilities of the various candidates for the role, including their range of services, costs, quality, and control of confidentiality. Specific organizations cannot be reasonably identified at the national level for the role of brokers, and competition for these roles is beneficial to the quality of the data system. In relation to hospital data, individual institutions are in the best position to understand underlying factors in their data. Non-institutional users of the data are ill-advised to proceed with data analysis until they obtain the institutions, insights on such factors as trends and their causes. Therefore a CHIS would need mechanisms for ensuring that hospitals are consulted by users of hospital data; and in addition, that access to the data would be appropriately controlled by the institution. Possible mechanisms for controlling access to hospital data include:

(1) Release of individual hospital data only with the consent of the hospital;

(2) Notification of hospitals of requests for their data, with an opportunity for the individual hosptial to comment on a proposed study;

(3) Voluntary participation by hospitals as data suppliers; and

(4) Establishment of data request review panels with broad representation.

Confidentiality

Security would be a major problem in any national electronically interconnected data system, and breaches of security could have very damaging personal consequences, assuming that patient identification would necessarily be included in at least some components of a CHIS. Security measures for such a massive system would be neither simple nor inexpensive if an individual's right to privacy were to be fully protected. Hospitals presently rely on the standards of the Joint Commission on Accreditation of Hospitals as well as legal standards and systems for protection of medical record information to assure the confidentiality of data. But hospitals would not be able to protect patient confidentiality once patient data entered a centrally controlled CHIS.

Development of a CHIS

A CHIS under strong federal control would effectively stifle state and local variation and experimentation with alternative data base content, editing, organization, and application approaches. Centralized control would potentially result in a major loss of effectiveness. We recognize that some mechanism is needed to share learning experiences and to avert unnecessary duplication of effort. Therefore, current AHA activities are complemented by and coordinated as much as possible with activities of other national associations, the federal government, commercial data services, and state-level nonprofit health data consortia, among others.

Planning and Research Functions of CHIS

One of the primary advantages of planning and research efforts is the maximum opportunity they provide for application of data, with special emphasis on support for local provider and other local area policy-makers' particular information needs. Therefore, a widely varied and locally-oriented base for this function is most appropriate, with the private sector taking the lead and government lending support where national needs for data have been unmet.

Mandatory Versus Voluntary Participation

For any health data system, mandatory hospital participation would have the advantage of assuring the size of a data base. There are, however, significant disadvantages to mandatory participation. It would:

(1) Prevent competition for relevant aspects of hospitals' data business;
(2) Increase system costs;
(3) Lower the data system's responsiveness to hospital and local area information need;
(4) Reduce the appropriateness of the data in solving local problems, perhaps making it marginal;
(5) Potentially prevent certain hospitals from devoting resources to higher priority needs in their communities; and
(6) Diminish the quality of data input as a result of negative incentives for individual hospitals to participate fully

CONCLUSION

The American Hospital Association appreciates this opportunity to present its views on the concept of a coordinated health information system and would be pleased to provide any further information or assistance that may be requested.

OFFICE
OF
POLICY STUDIES

POLICY BRIEF

Policy Brief Number 35

Integrated Data Management Systems
Descriptions and Policy Concerns

March 10, 1981

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INTEGRATED DATA MANAGEMENT SYSTEMS
DESCRIPTIONS AND POLICY CONCERNS

Policy Brief No. 35

Executive Summary

Since October 1977, the Health Care Financing Administration (HCFA) has awarded grants to develop integrated data management systems in eight states: Iowa, Maine, Minnesota, Missouri, New York, South Carolina, Vermont and Massachusetts.

The basic purpose of each project is the development of a clearinghouse for hospital inpatients' billing and discharge data, linked on an individual patient basis. The clearinghouse data would be computerized and made available to a variety of potential users including: hospitals, planners, researchers, state and federal regulators, and private and governmental third party payors.

Possible uses for the data include claims payment (under some systems), case finding for medical research studies, and studies related to: case mix adjusted payment, patient origin, market share, bed need and epidemiology.

The Integrated Data Management System demonstration projects deserve thoughtful attention, both because of the level of resources required for their development and operation and because of the potential uses and misuses for such systems. To evaluate health data systems in general (whether proposed, demonstration or operational), AHA has developed criteria which call for a review of data system usefulness and appropriateness of use, confidentiality, flexibility, adaptability and cost.

Application of these criteria to the individual IDMS demonstration projects yields a number of potential policy concerns related to IDMS cost/benefit ratios. Because the IDMS demonstrations have apparently not been preceded by systematic, detailed assessments of users' information needs, it becomes especially important to monitor the quantity and quality of data uses under the IDMS demonstrations. Will they be sufficient to justify the costs? Would less costly data systems suffice? Costs should be recognized to include not only financial costs; but also, costs in the form of disadvantages of IDMSs.

Potential key disadvantages of centralized, comprehensive patient care data bases include confidentiality breaches, encouragement of low quality research and excessive regulation, the slowing of hospital cash flow and the discouragement of competition for hospitals' data business. These potential problems are being avoided currently, to some degree, by the voluntary nature of most IDMS demonstrations and by IDMS policies and procedures regarding data release.

A key policy concern, however, is whether hospital participation will remain voluntary and whether present and future data release policies will continue to ensure confidentiality and high quality data research and analyses.

American Hospital Association
Office of Public Policy Analysis

INTEGRATED DATA MANAGEMENT SYSTEMS

DESCRIPTIONS AND POLICY CONCERNS

Policy Brief No. 35
March 10, 1981

BACKGROUND AND PURPOSE

Since October 1977, the Health Care Financing Administration (HCFA) has awarded grants to develop integrated data management systems in eight states: Iowa, Maine, Minnesota, Missouri, New York, South Carolina, Vermont and Massachusetts. The basic purpose of each project is the development of a clearinghouse for hospital inpatients' billing and discharge data, linked on an individual patient basis. The clearinghouse data would be computerized and made available to a variety of potential users including: hospitals, planners, researchers, state and federal regulators, and private and governmental third party payors. Possible uses for the data include claims payment (under some systems), case finding for medical research studies, and studies related to: case mix adjusted payment, patient origin, market share, bed need and epidemiology.

HCFA has also awarded the American Health Planning Association a grant for the development of educational materials for health planners on the use of IDMS data. In addition, HCFA has awarded a grant for the development of a data system to produce comparative office practice reports for participating physicians in New Hampshire.

In previous policy briefs, AHA staff have described the IDMS concept, presented AHA's model for evaluating health data initiatives, applied the model to the IDMS concept generally and discussed the tentative federal evaluation plan.[1] This policy brief describes and contrasts the individual IDMS projects. This brief also raises policy concerns over IDMS by applying AHA's evaluative model to specific IDMS efforts.

IDMS PILOT PROJECTS: CHARACTERISTICS AND VARIATION

Despite their common purpose of creating centralized, computerized data bases of individual inpatients' billing and discharge data, the IDMS projects differ in significant ways. The following sections discuss the variation in terms of: sponsorship; participation rules; timetables and status; data base content and output; merger; flow and transmission of data; and costs and financing.

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[1] Integrated Data Management Systems, Office of Public Policy Analysis, American Hospital Association, March 10, 1980.

Federally Sponsored Health Data System Intiatives, Office of Public Policy Analysis, American Hospital Association, October 1980.

Integrated Data Management Systems Preliminary Evaluation Plan, Policy Brief No. 33, February 1981.

State-Level Sponsorship: Of the eight demonstration grantees, two are government agencies and six are private organizations, including two hospital associations (Exhibit A). In most of the states, hospital participation in the development of the billing and discharge data base is voluntary. However, it is interesting to note that voluntary participation is not equivalent to private sponsorship of the project. In South Carolina, for example, the data system is operated by the State Division of Research and Statistical Services; but hospital participation is voluntary. In contrast, Maine's data system is operated by the private Maine Health Information Center, however, a state hospital disclosure law, which predates the act, requires hospitals to submit discharge data for creation of a central data base. (Hospitals comply through the McAuto discharge abstract service.)

Timetables and Status: The planned durations of the projects range from 3-5 years. Most were initially funded in or after October 1979 (Exhibit A). The New York project is at the most advanced stage, having been intially funded in October 1977. The Iowa, Maine, Missouri, South Carolina and Vermont projects are building on pre-IDMS statewide discharge data systems (Exhibit E). However, most of these and the remaining projects are only at an early state of integrated system design and implementation.

Data Base Content and Output: All of the project data bases will contain individual patients' billing data (generally the UB-16 data elements) and discharge data (UHDDS and PHDDS elements). The Maine, Minnesota and New York systems will also maintain hospital financial data, consistent with state laws or regulations concerning hospital disclosure and rate review. The Maine, Vermont and South Carolina data bases will include some combination of demographic data and cooperative Health Statistics System (CHSS) data elements (e.g., manpower, facilities and vital statistics data) (Exhibit C).

There is variation among the projects in terms of the predominant type of output that would be supplied to users. Maine, Vermont and New York represent interesting contrasts. In the New York system, with approximately 2.6 million community hospital discharges annually, the most feasible kind of response to special data requests may well be tailored subsets of basically raw data, sent to users on magnetic tape. In contrast, the Main Health Information Center would prefer to produce customized reports for users (rather than raw data tapes). All three programs plan to also produce routine statistical reports. It is noteworthy that Maine and Vermont plan to produce reports on small-area variation in per capita use of health care resources.

Data Merger and Flow: The demonstration projects vary significantly in terms of the point at which billing and discharge data are merged and the flow of data among hospitals, payors, discharge abstract services and the data clearinghouse (Exhibit D). In the Iowa and New York projects, for example, data will be merged at the clearinghouse. However, at least under the magnetic media or electronic data transmission systems under development in other states, billing and discharge data will be merged at the hospital, before transmission to the clearinghouse. In some states, billing data will pass through the clearinghouse on its way to third-party payors (Iowa, Maine, Minnesota and Missouri). To expedite claims payment, the Iowa clearinghouse will relay a copy of the billing data to payors for payment without first merging with the discharge data. In other states, billing data will be supplied to the clearinghouse by third-party payors (as in New York, for example) or will be submitted by hospitals in separate streams to payors and the clearinghouse (Vermont).

Similar variation exists with regard to the flow of discharge abstract data. Under certain data integration models in some of the states (New York and Maine, for example), the data clearinghouse will purchase abstract data from discharge abstract services selected by hospitals. In Minnesota and South Carolina, the clearinghouse will supply computerized data to discharge abstract services (at least under some of the data flow models being tested). Under the data integration models in Iowa, the grantee will continue to be the state's primary discharge abstractor. In Vermont, most hospitals have been Commission on Professional and Hospital Activity (CPHA) subscribers; however, the IDMS grantee will collect billing and discharge data directly from hospitals and plans no relationship with CPHA.

Data Transmission: The IDMS projects are testing a variety of systems for data communication between hospitals and their associated clearinghouse (Exhibit D). Most depend on computer technology. In Iowa, for example, the clearinghouse will receive data on magnetic tape or diskette from hospitals with either inhouse computers or service bureau arrangements. For hospitals without computer services, terminals will be installed for remote entry of billing and discharge data. South Carolina is experimenting with direct, electronic communication between the hospital computer and the clearinghouse computer.* The Missouri project originally planned to test two hard copy transmission models besides the electronic transmission model. However, it has proven difficult to enlist hospitals to test nonelectric transmission. The New York system is based largely on tape transmission of patient data (for Blue Cross, Medicare and Medicaid** patients). However, for commercially-insured and self-pay patients, hospitals provide the clearinghouse with duplicate paper copies of claims.

Financing and Costs: Until now, HCFA grants have support 95 percent of the projects' developmental costs. Grants for FY 1980 totalled $5,594,427. The grantees originally expected that federal funding would continue at the 95 percent level throughout the 3-5 year project periods. Beyond that time, grantees anticipated that project continuation would depend on securing funds from other sources. However, it now appears that grantees will have to accelerate their plans for financial self-sufficiency.

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*CPU-to-CPU transmission.

**For patients from counties with Medicaid management information systems (MMIS).

Grantees were advised by HCFA in November 1980 that funds for all projects are expected to be more limited next fiscal year and that they should accelerate their timetable for financial self-sufficiency. The Minnesota Hospital Association was specifically advised to budget on the basis of 50 percent self-sufficiency for FY 1982. HCFA plans to base future funding decisions on projects' adherence to timetables specified in their work plans.

The New York experience presently provides the only clear guide to the probable operating cost level of IDMS programs. Having begun several years before the other projects, the New York project is the only operational demonstration. The state's annual operating budget of over $4 million will be financed by a 0.5 percent levy on hospital expenses. These funds will cover the state's operating cost for both the patient data and hospital cost data bases.

POLICY CONCERNS

AHA's Evaluative Model: Policy Brief No. 25 discusses criteria by which health data systems should be evaluated. The basic criteria are:

- Capacity to meet user needs (data timeliness, accuracy, reliability and relevance).
- Confidentiality (both patient and provider).
- Appropriateness of application.
- Flexibility (users' ability to effect changes).
- Adaptability (not imposing organizational and hardware constraints on providers).
- Total cost (both data system and provider cost).

As noted earlier, most of the IDMS demonstration projects are at a fairly early stage of development. Consequently, one cannot yet say with certainty how the systems will perform in terms of the evaluative criteria. However, the criteria can be reasonably applied at this point to raise policy concerns with regard to IDMS. Policy concerns are discussed in the remainder of this report.

Capacity to Meet User Needs: All of the IDMS projects will edit data before it enters the data base. The Iowa and South Carolina projects also plan some special research into the quality level of billing and discharge data. The South Carolina project will also experiment with educational and management engineering approaches to data quality improvement (Exhibit C). It is noteworthy also that the Iowa program will assess the relative merits of CPT-4 vs. ICD-9-CM procedure coding (including the relative usefulness). The Maine and Vermont systems will be augmenting the value of the utilization information by linking it with small-area demographic data.

In reviewing available information on the IDMS projects, it is not clear that the projects are founded on explicit, indepth analyses of the types of uses and users to be served by the data bases. Such analyses would appear to be prerequisites for rational decision-making on whether and how to design and implement central data bases. Even without explicit front-end decisions on major uses and users, experience under the pilots should help to clarify the data base content, systems design and overall resource requirements associated with various uses under an IDMS.

With regard to the usefulness of IDMS, key policy issues are:

- Without the major uses and users of integrated data management systems being explicitly defined, can various IDMS approaches be effectively evaluated, individually and collectively, in comparison with other approaches?
- Will the frequency and value of the uses of IDMS data bases justify the expense needed to develop and operate comprehensive, timely, high-quality data systems?
- Will voluntary participation prove compatible or incompatible with the goal of comprehensive, statewide data bases? On the other hand, will mandatory participation prove compatible or incompatible with IDMS cost, flexibility, usefulness, and adaptability goals?

Confidentiality and Appropriateness of Use: Each IDMS project is specifically addressing the issue of data confidentiality. The projects differ in terms of patient and provider identifiers kept on the data bases. South Carolina and New York represent contrasting approaches. The South Carolina system maintains neither patient nor provider identifiers, while the New York system does. However, in New York, requests for data involving items classified as "deniable" (including patient and provider identifers)* must be reviewed by the Data Protection Review Board (representing consumer groups, hospitals, PSROs, medical societies, bar associations, medical records associations, academic health researchers, government agencies, HSAs, Blue Cross/Blue Shield and commercial insurance companies). The Review Board then makes a recommendation to the state health commissioner, whose decision can be overruled by the Review Board. In Maine and Iowa, patient identifiers are strictly confidential and providers have ultimate authority over the release of their nonfederal data in identifiable, aggregate form. In Maine, groupings of fewer than three records will not be released (New York sets six as the minimum).

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*Deniable items are: medical record and admitting numbers and dates, dates of surgery and discharge, 3rd party payor ID number, address, birth date, accident date, hospital identity and groupings of fewer than 6 records.

Early in its history, the New York IDMS project denied HCFA access to certain data on even federal patients. A major controversy ensued, with New York State and HCFA ultimately agreeing that HCFA could routinely access only data to which it was legally entitled (basically federal patient data). For other types of data requests, HCFA must go through the same review process as any other party.

A major area of policy concern should be the appropriateness of the uses of IDMS data. The lengthy list of federal agencies expected to be regular or occasional users of IDMS data underscores the concern that readily accessible statewide patient data bases could foster overregulation of hospitals (Exhibit F). This concern is offset to some extent by the limitations on federal access to the data. Nevertheless, the potential remains through the direct or indirect effects of data analysis by governmental and nongovernmental groups. Another concern stems from the fact that IDMS data bases may facilitate low-cost research. On the surface, this is a beneficial effect. However, IDMS could also facilitate low-priority, poor quality research unless appropriate safeguards are provided. Review boards are one approach, and in fact on at least one occasion the New York DPRB considered the quality of a certain proposal in deciding to approve a request for deniable data. However, concern has been expressed by DPRB board members and IDMS staff over the defensibility of a decision to deny access or priority on the basis of poor proposal quality. The issues are complex, but the need for such review authority is parallel to the need to consider the quality of research proposals in awarding research grants.

In summary, key policy concerns with regard to confidentiality and appropriateness of data use under IDMS are:

- Will confidentiality safeguards prove sufficient, considering the increase in vulnerability to certain confidentiality breaches as data bases become more centralized?
- Will the existence of statewide patient data bases foster overregulation of health care, considering current limits on state and federal governments' access to IDMS data?
- Without explicit written criteria, how successful will IDMS programs be in preventing inappropriate data uses and low-quality research?
- Will the existence of statewide data bases encourage over time legislative relaxation of limitations on state and federal governments' access?
- Will IDMS encourage more, high quality health research, with effective safeguards against low-quality research?

- Will the mere existence of a voluntary integrated data system result over time in government efforts to mandate and/or administer some or all system components?

Users' Ability to Effect Changes: The IDMS projects seem to be taking reasonable steps to ensure user input into system design and operation. The mandatory New York system has broadly constituted advisory panels on overall policy, system input and system output. The key policy concern, though, is how flexible the systems will prove to be in practice.

Adaptability: In general, it does not appear that the IDMS projects are imposing EDP or organizational constraints on hospitals. As noted earlier, hospital participation is voluntary in most of the projects. Also, the IDMS systems are being designed to be compatible with a variety of present and future hospital EDP capabilities. The key policy concern is whether the systems will continue to be adaptive.

Cost: A number of potentially significant direct cost concerns should be considered: the developmental and operational costs for the clearinghouse, comparative costs of alternative data systems plans, hospitals' costs for data assembly and transmission and impacts on hospital cash flow. As evidenced by the New York clearinghouse's experience, the developmental and operational costs for a clearinghouse are significant, despite heavy reliance on existing sources of computerized billing and discharge data. These costs need to be considered in light of the usefulness of the data system. The total costs (clearinghouse plus hospital) should also be compared with the costs of alternative means of meeting users' data needs (e.g., statewide samples of merged patient billing and discharge data or nonmerged data bases). The demonstrations intend to make extensive use of electronic or magnetic media data transmission methods. Nevertheless, there should be concern over whether the systems accommodate the most efficient modes of data transmission. As noted earlier, data for certain categories of patients will be transmitted in hard copy form in certain states.

Potential cost-savings should be recognized. Several systems are planning "paperless" systems by which hospitals can bill third-parties. Automated billing would be either through the clearinghouse as in Iowa, Maine, Minnesota and Missouri or directly from the hospital to the payor, as in South Carolina. Offsetting effects could occur. Automation bears the potential of reducing administrative costs and improving cash flow, but merger of billing and discharge data and transmission through an intermediary could conceivably slow hospital cash flow. It is interesting to note that the Iowa clearinghouse plans to routinely transmit electronic copies of the billing data on to payors before merging the clinical and billing data.

IDMS programs may adversely affect costs in an indirect way, by discouraging competition for hospitals' data business. Even though the projects commonly plan to rely on tapes from CPHA, McAuto and other abstract services where possible, desire for organizational growth and/or pressures for financial self-sufficiency may lead the projects over time to compete with CPHA, McAuto and other such services for hospitals' discharge abstract business. Such competition could become unfair and contrary to the public interest to the extent that federal subsidies provide the programs with competitive edges or that hospital participation becomes mandated by law.

In summary, the key policy concerns in the cost-area are:

- Total cost relative to value.
- Comparative advantages/disadvantages of less expensive types of data systems.
- Impacts on hospital administrative costs and cash flow.
- Impacts on competition for hospitals' data business.

Policy Issue Summary: The Integrated Data Management System demonstration projects deserve thoughtful attention, both because of the level of resources required for their development and operation and because of the potential uses and misuses of such systems. To evaluate health data systems in general (whether proposed, demonstration or operational), AHA has developed criteria which call for a review of data system usefulness and appropriateness of use, confidentiality, flexibility, adaptability and cost.

Application of these criteria to the individual IDMS demonstration projects yields a number of potential policy concerns related to IDMS cost/benefit ratios. Because the IDMS demonstrations have apparently not been preceded by systematic, detailed assessments of users' information needs, it becomes especially important to monitor the quantity and quality of data uses under the IDMS demonstrations. Will they be sufficient to justify the costs? Would less costly data systems suffice? Costs should be recognized to include not only financial costs; but also, costs in the form of disadvantages of IDMSs.

Potential key disadvantages of centralized, comprehensive patient care data bases include confidentiality breaches, encouragement of low quality research and excessive regulation, the slowing of hospital cash flow and the discouragement of competition for hospitals' data business. These potential problems are being avoided currently, to some degree, by the voluntary nature of most IDMS demonstrations and by IDMS policies and procedures regarding data release.

Another key policy concern is whether hospital participation will remain voluntary and whether present and future data release policies will ensure confidentiality and constructive data research and analyses.

Exhibit A

Integrated Data Management Systems
Hospital Data Demonstration Projects[1]

Sponsor	Type of organization	Initial grant	Demonstration period
Iowa Hospital Association	Private	June 1980	3 years
Maine Health Information Center	Private	October 1979	5 years
Minnesota Hospital Association	Private	October 1979	3 years
Missouri Health Data Corp.	Private	January 1980	4 years
New York Office of Health Systems Management	Governmental	October 1977	4 years
South Carolina Division of Research and Statistical Services	Governmental	October 1979	4 years
Cooperative Health Information Center of Vermont	Private	October 1979	4 years
Blue Cross of Massachusetts	Private	February 1981	See note 2

Notes: 1/ HCFA is also funding a comparative physician practice data system in New Hampshire and an American Health Planning Association educational project on uses of IDMS data.

2/ As of the date of this report, the Massachusetts staff were in the process of finalizing arrangements with HCFA and the various parties to be involved at the state level. Consequently, more detail will be provided in subsequent reports.

Exhibit B

Integrated Data Management Systems
Hospital Participation and Discharge Abstracts Involvement

State	Hospital participation	Pre-IDMS discharge abstract services	IDMS Relationships with discharge abstract services
Iowa	Voluntary	Hospital association mainly. Also, CPHA and McAuto	IDMS will be an abstractor. IDMS will also purchase data from CPHA and McAuto
Maine	Required by state law	McAuto	1. Under the electronic transmission pilot, IDMS will supply data to discharge abstract services 2. In creating the larger merged data base, IDMS will purchase data from discharge abstract service
Minnesota	Voluntary (except for cost and revenue data required by rate review Act)	Various	IDMS will supply data to discharge abstract services
Missouri	Voluntary	IDMS sponsor mainly. Also CPHA and McAuto	Not decided
New York	Required by state law	Hospital Association, CPHA, McAuto	IDMS purchases data from abstract services
South Carolina	Voluntary	CPHA mainly	1. For electronic transmission pilot hospitals, IDMS will supply data to abstract services 2. At least for now, state will continue to purchase abstract data for nontest site hospitals

Exhibit B (cont)

Integrated Data Management Systems
Hospital Participation and Discharge Abstracts Involvement

State	Hospital participation	Pre-IDMS discharge abstract services	IDMS relationships with discharge abstract services
Vermont	Voluntary	CPHA mainly	No relationship
Massachusetts	Voluntary	6 discharge abstract services	NA

Exhibit C

Integrated Data Management Systems
Other Noteworthy Project Goals[1]

State	Other Goals
Iowa	1. Evaluate feasibility and cost effectiveness of inhospital computerized patient data systems, to eliminate need for data merger at clearinghouse.
	2. Improve billing and discharge data flow in sample of hospitals without computer support.
	3. Evaluate impact of educational programs on discharge data quality.
	4. Assess relative merits of ICD-9-CM vs. CPT-4 procedure coding systems.
	5. Assess feasibility of extending IDMS concept to outpatient, emergency room and long-term care data.
Maine	1. Also integrate demographic, CHSS[2] and hospital financial data.
	2. Extend progress in production, feedback and use of small area, population-based utilization indicators.
	3. Determine feasibility of replicating Maine's system elsewhere.
Minnesota	1. Develop simulation models for use in implementing IDMS elsewhere.
New York	Test AHR.
South Carolina	1. Also integrate CHSS data.
	2. Test reliability and validity of data elements for initially federal patients.
Vermont	Also integrate CHSS and small-area demographic data.

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[1] Besides the creation and maintenance of patient billing and discharge data bases.

[2] Cooperative Health Statistics System (forerunner of IDMS pilots in various states).

Exhibit D

Integrated Data Management Systems
Data Transmission Models

State		Hospital-to-clearinghouse transmission and merger models
Iowa	Model 1:	For hospitals with computer service: unmerged billing and discharge data to be sent via magnetic tape or diskette.
	Model 2:	For hospitals without: remote terminals for billing data, tape from abstract service.
Maine	Model 1:	Merged data sent by remote CRT (for selected hospitals).
	Model 2:	Tapes from third-party payors and discharge abstract services (for others).
Minnesota		Merged data sent by tape or CRT, depending on whether hospital has computer capability.
Missouri	Model 1:	Hard copy, merged discharge and billing data mailed to clearinghouse.
	Model 2:	Discharge data mailed to clearinghouse. Billing data sent by telecopier.
	Model 3:	Inhospital CRTs or mini-computers to merge and send data.
New York		Discharge data from abstract services. Blue Cross, Medicare and Medicaid billing data from the third-parties. Hospitals provide duplicate hard copy claims for other patients.
South Carolina	Model 1:	Merged billing and discharge data wired from hospital computer to clearinghouse computer (CPU-to-CPU transmission).
	Model 2:	Merged billing and abstract data sent to "mini-clearinghouse," which then sends tape to main clearinghouse.
	Model 3:	Merged billing and clinical data sent to hospital-based "mini clearinghouse," which then sends tape to main clearinghouse.

Exhibit D (cont)

Integrated Data Management Systems
Data Transmission Models

State		Hospital-to-clearinghouse transmission and merger models
Vermont	Model 1:	For hospitals with computer capabilities, merged data sent by diskette.
	Model 2:	For hospitals without computer capabilities, portable terminals will be used to transmit merged data.
Massachusetts		NA

Exhibit E

States with Pre-IDMS Comprehensive Discharge Data Sets

Iowa

Maine

Missouri

South Carolina

Vermont

Massachusetts

Exhibit F

Federal Agencies Expected to be Users of Integrated Data Management Data

Health Care Financing Administration

- Office of Beneficiary Services (OU)
- Office of Public Affairs (OU)
- Office of Management and Budget (OU)
- Office of Research, Demonstrations and Statistics
- Office of Financial and Actuarial Analysis (OU)
- Office of Statistics and Data Management (RU)
- Office of Demonstrations and Evaluations (OU)
- Office of Research (OU)
- Office of Legislation and Policy (OU)
- Health Standards and Quality Bureau
- Office of Professional Standards Review Organizations (OU)
- Office of Standards and Certification (OU)
- Office of Policy Development and Coordination (OU)
- Office of Program Support (OU)
- Bureau of Quality Control
- Office of Quality Control Programs (OU)
- Office of Program Validation (OU)
- Office of Financial Analysis (OU)
- Office of Systems Analysis (OU)

Notes: "RU" denotes expected regular user.
"OU" denotes expected occasional user.

Exhibit F (cont)

Federal Agencies Expected to be
Users of Integrated Data Management
Data

- Bureau of Program Operations
    - Office of Program Administration (RU)
    - Medicaid/Medicare Management Institute (OU)
    - Office of Standards and Performance Evaluation
    - Office of Methods and Systems (OU)
- Regional Offices
    - Region I - Boston (RU)
    - Region II - New York (RU)
    - Region IV - Atlanta (RU)
    - Region V - Chicago (RU)
    - Region VII - Kansas City (RU)
- Bureau of Program Policy
    - Office of Reimbursement Policy (OU)
    - Office of Coverage Policy (OU)
    - Office of Eligibility Policy (OU)
- Bureau of Support Services (OU)

National Center of Health Services Research (RU)

National Center for Health Statistics (RU)

Health Resources Administration

- Bureau of Health Planning (RU)

Congressional Budget Office (OU)

General Accounting Office (OU)

Exhibit G

Integrated Data Management Systems
Source of Patient Data Release Policy

State	Source
Iowa	Iowa Hospital Association (grantee) for now, aided by Project Advisory Council
Maine	Maine Health Information Center (consortium grantee), lesiglature.
Minnesota	Minnesota Hospital Association (grantee)
Missouri	Missouri Health Data Corporation (grantee, consortium)
New York	New York State Office of Health Systems Management, aided by Data Protection Review Board and Council on Hospital Information Policy (both broadly constituted)
South Carolina	Statewide Hospital Care Information Task Force
Vermont	Cooperative Health Information Center of Vermont (grantee)
Massachusetts	Project steering committee (representing hospitals, insurers; the Massachusetts Health Data Consortium and state government

Mr. **Scheuer**. As to the difference of the data, wouldn't an appendicitis be the same on the west as on the east coast? A hysterectomy should be the same in Philadelphia as in Grand Island, Nebr. Patient care standards and patient care needs should be the same pretty much universally.

There are differences in hospitals, whether it is a tertiary hospital or a small community hospital or a nursing home. There are levels of intensity of health care, but I don't understand this differential that you have talked about on the second page where you believe that these data systems are evolving according to State and local needs. It seems to me we are going to end up with 50 or more different systems that aren't compatible. There won't be communication between the systems. They will lose the epidemiological advantages of having a national system in things like smoking and cancer, on the impact of the environment, the air we breathe, the water we drink, of certain industrial uses.

Why shouldn't this be a national web or a national network that all these institutions are plugged into, where we can retrieve national data?

I don't understand why we want to "evolve the system according to State and local needs."

Mr. **Manzano**. I guess the point is that you are correct. There is a body of information which needs to be collected and understood at a national level. That volume of information is probably a synthesis of what is collected at a State level or a local level or at the hospital level, and that the ultility of information at each level is necessarily different.

For instance, the utility of information at the hospital level most immediately is used in its particular application to a given patient. At the national level it is the aggregation of certain kinds of information that provides the information that is necessary to review the sorts of things you have talked about, the characteristics of the distribution of illness, the characteristics of the nature of treatment, but that is a level of need which is somewhat different, and I think differentiated at every level between the national and local in patient situations.

For instance, in the area such as the need for planning purposes, obviously the mix of what occurs in a community has a particular meaning within that community when aggregated at the national level may not be relevant to particular instances of the community, and on the patient basis the gross data on patient treatment may not be applicable to the particular patient, and that is what I am talking about, the level of need is different, and the way the data is used is different. But you are correct, Mr. Chairman, in that there are——

Mr. **Scheuer**. Look, there are lots of ways, countless ways in which data is used.

Mr. **Manzano**. Yes.

Mr. **Scheuer**. I am not convinced that we shouldn't have a national system that would provide communication, a communication network under which all health services delivered to institutions would be plugged. And then in terms of retrieval, an investigator could pick out, could examine all nursing homes, or all nursing homes in a particular region, all nursing homes nationally, compare them, or he could take all health service institutions in one region and compare them vertically.

There are many, many, many different ways of using that information, and some of them would be local and regional. But it seems to me we ought to construct a national system which would be susceptible of being used in all of the various varieties of ways that you would describe. It would be essentially a national system in which all health care institutions would be plugged.

Mr. **Manzano**. Well, there are in effect data bases at that level, the national level, that are, in effect, accumulated from existing systems and that, I think, is inherent in the idea of the cooperative development of health care and hospital information, and it has based itself upon the fact that individual institutions have particular kinds of system needs that feed into system data needs at the local bases that feed into systems needs at State bases and at the regional and then ultimately national.

A good example, of course, is mortality-morbidity data, which is processed in effect through cumulative systems through individual institutions, through States and into the Federal level. I think that that kind of model allows for the flexibility that I think is vital to insure that at every level the particular kinds of focuses and needs are addressed, and that there not be a distortion of it in order to comply with a very rigid national system.

I think the point is the level of information needed is not always the same, and it is not necessary to, I think, develop a rigorously centralized and controlled system to achieve what you seek.

Mr. **Scheuer**. Continue with your testimony.

Mr. **Manzano**. That is all I have to say in terms of oral testimony.

Mr. **Scheuer**. I am going to turn the chair over to my cochairman Congressman Walgren.

Mr. **Walgren** [presiding]. Mr. Brown.

Mr. **Brown**. Mr. Manzano, I very much appreciate your testimony, and personally I have no great difficulty in accepting the philosophy and policy positions which you reflect. The dialog between you and Chairman Scheuer to some degree is a semantic difficulty more than a policy difficulty. The practical fact is that there is absolutely no possibility, at least within this administration of developing a national integrated comprehensive health information system. You, I think, reflect the views of this administration that this is an undue and unnecessary level of Federal intervention in the system.

Nevertheless, what we are interested in is what positive roles we can play here, and I want to pose two questions to you, two possibilities I would like you to comment on.

If you have been in attendance, you will have noted that at least two and possibly more of the witnesses have made a strong expression of the fact that nothing would take place here without a high element of public-private cooperation in the planning and development of a system. Do you think that it would be feasible to take some forward steps in improving data systems and, through that, the delivery of health care services to the American people through some positive steps at building this kind of a cooperative approach to the problem?

Mr. MANZANO. Yes, I do. I think that it would be useful if there was a mechanism that would provide for sort of an oversight policymaking group, perhaps under some kind of Federal leadership, that would involve a broad band of entities that are responsible now and have ongoing operations in health data, and that it could, I think, serve as a useful identifier of needs at various levels. It could also serve in terms of identifying kinds of situations where Federal assistance would stimulate appropriate development, and I think there is definitely a gain from something of that kind.

Mr. BROWN. There is a category of Federal obstacles which might be removed in some instances, I presume?

Mr. MANZANO. I think that there is—I don't know if you would call them obstacles, but I do think that if there is a system that permits greater input from other sources, and allows for greater recognition of diverse ways of doing things, that would be a beneficial position for the Government to be taking nationally.

Mr. BROWN. That is a very sound philosophy that you are describing, that is, the idea of local participation in control and autonomy and diversified voluntary networks rather than a centralized, federally mandated system. There is philosophically nothing wrong with that concept, except when it is used as a coverup for being unwilling to actually take steps necessary for the public welfare. I know the American Hospital Association would never be guilty of that, but there might be some agencies that would.

Let me ask you one other thing. The previous witness indicated that to some degree other HSA's instead of being a positive factor toward the encouragement of improved health information systems, or data management systems, whatever we choose to call them, instead of being a positive factor, was in fact a negative factor, that the process of application and clearance and so forth tended to discourage or inhibit hospitals and perhaps other institutions from proceeding.

I want to ask you if that has been your own experience, and if so, are there steps up to and including the administration's position of abolishing HSA's that might be helpful in remedying that problem?

Mr. MANZANO. Mr. Brown, the question appeared to be asked in the context of a comprehensive on-line data system, a management information system within institutions such as that which the gentleman from Technicon was describing to you.

Mr. BROWN. Yes.

Mr. MANZANO. Those are quite expensive systems. They may not at all be applicable or necessary in the majority of institutions.

There are quite a bit of costs involved with the introduction of either that system or if the hospital were to introduce its own system. These capital costs which the HSA's have focused on really involve the acquisition of fairly expensive computers. Obviously, the present system is so designed to review the expenditure to make sure it is appropriate.

I am sure in that sense it is inhibiting, but I want to put it in the context of the subject of the committee's discussion, this business of developing a coordinated system useful at all levels, and I am not certain that it is necessary in order to provide the kind of information that all hospitals have such operational on-line systems, and so I would not suggest that—if a hospital absolutely is convinced that that is what it needs, it can go through that existing process, and we can argue the merits of the process as to whether or not it is making or assisting in improving the quality of decision.

But whether that HSA was there or not, that hospital should, and does, make that kind of a review. Is this a cost-effective investment of scarce resources, particularly at a time where the whole question of investment capital expansion in health care is a community as well as a national concern?

Mr. BROWN. You are saying they make the same kind of analysis of this capital expenditure as they would for a new wing on the building or a new CAT scan or any other expensive item?

Mr. MANZANO. I think that you always have to match your resources against the options that you have, and I don't know in a particular instance as to how a hospital would evaluate, the competing alternatives that would be presented at any one time.

Mr. BROWN. Just one final question. From your statement, I gather that the American Hospital Association has its own data collection system and network, presumably operated on a voluntary basis with member hospitals. Is that system one that would provide useful background information to the kind of discussion that we are having here? Would it give lessons as to some of the problems or obstacles that would be encountered in any establishment of a comprehensive health information system?

Mr. MANZANO. I really believe it does, Mr. Brown, and perhaps Mr. Killingsworth, who has been responsible for that, can describe how we have gone about it.

Mr. BROWN. I would appreciate it if he would, briefly.

Mr. KILLINGSWORTH. Basically, I think there are two components that are relevant: first, the actual data collection component which consists of our annual survey of hospitals, which we conduct every year and have for many years now. That survey is different for the collection of 1980 data than it has been in the past in the sense that it has been largely expanded.

I think the lesson that is relevant here from that expansion was that we recognized early on that we would need to be able to have participation from various sectors in that expansion effort. Therefore, we did a little more than explain to parties at the State level which data items we required for our work in maintaining the data base that we have maintained over time for the Nation, and we then left it up to State-level groups, State hospital associations, CHS agencies and health departments to determine how the data would be collected toward fulfilling that data set that we needed.

And they also had the option to add data items based on their own local needs, and so far we haven't completed that process for 1980 data, but so far all indications are that that process is going very well, and I think it is largely due to the fact that we did not dictate to State-level groups that information should be collected in addition to our own or how.

That dovetails with the data network project, which is essentially an effort to reduce the collection burden among hospitals by sharing in an effective way data that already exists. The HA made a large portion of its annual survey data base available to public-private sector groups, commercial firms and also allied associations and other membership groups by essentially putting that data base on an outside time-sharing computer sytem that people could sit at a terminal, log into the data base and query it.

It reduced the amount of time that it has taken people in the past to access the AHA data and also increased their ability to ask questions, to analyze the data base, actually sit there and get answers to questions that are going to be helpful for the decisions that they have had to make.

We think the network project has been succcessful so far because it mounts data that exists and allows people to answer the questions that they need, cross sectors and at the same time allows them to build data bases at their level which are useful to them, to which they control access and we don't, so it was an effort to share data through an electronic mechanism taking advantage of technology that exists.

Mr. **Brown**. Thank you. It sounds like you practice what you preach in this regard.

Mr. **Manzano**. I hope so.

Mr. **Brown**. I have no further questions.

Mr. **Walgren**. Thank you, Mr. Brown. I wanted to ask whether the data collection effort, Hospital Data Center, is involved in the cost containment effort by the Hospital Association, and if so, how.

Mr. **Manzano**. Well, we do provide—we have two surveys, basically. One is the annual survey and one is the panel survey, the hospital panel survey. It collects information which we utilize in monitoring the nature of the hospital costs and how they are changing over time. That panel data is utilized in producing monthly reports which are used to feed into voluntary effort activities at State and national levels.

Mr. **Walgren**. Has the Hospital Association developed any cost-effective ways of handling data that they would recommend to local hospitals as a way of reducing their costs?

Mr. **Manzano**. If you are talking about assisting hospitals in particular in their own management and operations, I would say yes. We have a system which is called Monitrend, which is carried out by our hospital administrative services activity, which in effect accumulates from hospitals certain measures of input and financial information, and produces that in ways that can be useful at the hospital level in managing particular departments in assessing what it can do to improve its efficiency and effectiveness, and that is available in some, I believe, 3,000 hospitals now participating in it.

Mr. **Walgren**. Can you describe that a little bit further for me?

Mr. **Manzano**. What I have done in effect over the last few questions, with Mr. Killingsworth's assistance, is to describe the major information activities which the AHA undertakes. We collect information on facilities and services. We collect information on financial and input factors, and what we find is that it is useful for hospitals if they can receive and have displayed and available to them information on a trend basis on what is occurring within their own institutions, their financial data, their management data, their personnel data.

It also helps them a lot because, in addition to showing them what they themselves are doing, we can show them comparative information, compare them with hospitals of like size groups, for example, or compare them with hospitals in similar categories. For instance, there is a report that children's hospitals get that, compare them to other children's hospitals, but what that mechanism does in effect is to try to establish not necessarily an establishment, but offer to hospitals comparative statistical information about themselves over time, and with other hospitals, which they can use in monitoring and identifying areas where perhaps the management could achieve some gains in productivity, gains in efficiency, gains in cost effectiveness.

Mr. **Walgren**. And that is done for the costs involved in managing information itself; is that true?

Mr. **Manzano**. Yes, we believe it does produce a significant savings to the institution in managing information. Well, for one thing, it would be very difficult for the individual institution to develop comparable data with other institutions, without having a central collector do that.

Second, there are certain efficiencies where they do not have to develop the data system themselves. They do not have to have the hardware. All they have to do is input information, and we can produce for them the kinds of useful reports that management needs.

There are other systems of that kind on the clinical side. For instance, the Commission on Professional Activities in Ann Arbor is an enterprise in which the HA's are actively involved, which collect clinical information from institutions and helps them monitor their own clinical performance, and to also compare themselves with other institutions, and serves as a vehicle for collection of probably the largest data base in the country of clinical information from institutions, and a data base which is made generally available at local levels. It has been made available to PSRO's. Planning groups can access that information, and there has been a long history of sharing that information in contract studies with the Federal Government.

Mr. **Walgren**. Thank you very much.

Was there anything you would like to add to that, Mr. Killingsworth?

Mr. **Killingsworth**. No, thank you.

Mr. **Walgren**. We appreciate your testimony and your patience.

Mr. **Manzano**. Thank you.

[Whereupon, at 12:45 p.m., the subcommittees adjourned.]

HEALTH INFORMATION SYSTEMS

THURSDAY, JUNE 4, 1981

House of Representatives, Committee on Science and Technology, Subcommittee on Science, Research, and Technology; Subcommittee on Natural Resources, Agriculture Research and Environment,
Washington, D.C.

The subcommittees met jointly at 9:10 a.m., in room 2325, Rayburn House Office Building, Hon. George E. Brown, Jr. presiding.

Present: Representatives Brown, Scheuer, Walgren, Shamansky, Sensenbrenner, Gregg, Skeen, and Schneider.

Mr. **Brown**. The subcommittee will come to order.

In the interest of time and because we have several witnesses this morning, we are going to move along as quickly as possible.

I have a brief opening statement for this morning's hearing which I would like to read:

Information has power and value to the extent that it can be expressed simply and clearly. Additional requirements include that it have meaning, bear on the problem at hand, and be made available within a usable time frame. These points have been made by several of the witnesses we have heard so far. Although information can be regarded as a necessity in arriving at a decision, it should not be the sole factor.

It appears that many of the decisions made today, whether they are personal or political, are often based on inadequte, and more often than not, unreliable information. Decisions related to health and its delivery do not appear to break this rule.

Although we try to do the best that we can, decisions about health, environment, and disease are based on relatively modest amounts of information which is very often of either poor or at least questionable quality, and I might say that that statement is based on several years of personal experience in this field. That this is still the case, in spite of considerable progress in the fields of information theory and communications science, is depressing.

There has been an information revolution which has occurred in the face of a data explosion. In my opinion, these happenings are still in the early phases of development. There is still time to influence development—conceptually, technologically, and organizationally.

That activity, in my estimation, is what these hearings are all about. The information system I have heard about for the past 2 days should be able to improve the gathering of information about health and expedite its processing, communication, and timeliness. It would also insure the clarity of valid and reliable observations. This has to occur, even though the information flows in several different channels. In order to make use of the information, it has to be organized systematically, so that the observations are both compatible and comparable.

We have heard in the last 2 days from witness after witness that a system to do this is technologically feasible. There are inhibitions and obstacles. Many of them are political, economic, and sociological. They should not be underestimated, but they also should not be considered insurmountable.

We have covered the areas of need and benefit and the issues and problems. The area that still remains to be considered is the matter of organization and planning. Several suggestions have been made, including the possible role that might be played by a private/public sector effort. It is my hope today that in the course of the hearing we will hear some suggestions along these lines.

Our first witness this morning will be Erica Drazen from Arthur D. Little, Inc. She will be followed by witnesses who will discuss two systems currently in operation that should provide us with information about planning. And after that will be Dr. Karen Duncan of Hospital Information Systems, and we are expecting Dr. Brandt, Assistant Secretary of Health to be the last witness this morning.

And before we invite Erica Drazen, I'd like to ask the distinguished chairman of the subcommittee, Mr. Scheuer, if he has any statements he would like to make.

Mr. SCHEUER. No statement at this time, Mr. Chairman.

Mr. BROWN. I believe Ms. Heckler has a statement.

[Opening remarks of Ms. Heckler follows:]

OPENING REMARKS OF HON. MARGARET M. HECKLER

Thank you, Mr. Chairman, I want to thank the chairman for holding these three days of Hearings on a most important topic. I regret that I was unable to attend the previous hearings, which I understand were very informative, but previous commitments in my district and here in Washington precluded my attendance.

I would like to make a few comments this morning since this issue is of such importance to the health professions and subsequently to all Americans.

There are a number of factors that have had great impact on the health services industry in the last two decades. The most important of these factors is the increase in cost and sophistication of health care, especially hospitalization.

I see two problems here. First of all, the issue of health care costs is extremely important. The systematic introduction of information technology to the health services industry can have a tremendous impact in this area. With the proper collection, analysis, and dissemination of health care information, Americans would have the opportunity to evaluate health care facilities and practices for both cost and quality of services. Computerized information systems provide the capability for such a service.

The use of information technology will assist not only the consumer, but the health services industry as well. The computer is equally useful in the rural doctor's office as it is in Mass General, one of the most sophisticated hospitals in the world. As the doctor's and the hospital's care become more effective and efficient, the costs associated with them will go down.

The second problem I wanted to identify, related to the increasing sophistication of health care, is the mistaken impression that increasing technological sophistication automatically means an improvement in health care. This is not necessarily the case. Increasing complexity leads to increasing specialization and fragmentation. It is not simply technical sophistication that we should seek, but rather a systematic, coordinated, technical capability linked with appropriate information technology that will provide the country with a truely superior health care system.

Previous testimony pointed out that the medical profession is 15 years behind the data, and 5-7 years behind other major industries in computer utilization. The two figures are related; doctors will only be able to catch up with the data as they make increasing use of computers. The medical profession must make a better effort in this area.

While I do believe that the health data collected by government agencies should be coordinated, I am not convinced that additional legislation is necessary. The Health Services Research, Health Statistics, and Health Care Technology Act of 1978 does seem to provide the necessary mechanism for "producing comparable and uniform health information and statistics."

Nevertheless, the fact that this issue continues to plague the industry (no pun intended), is reason enough to re-examine the issue through these hearings. I would like to thank the witnesses for contributing to these hearings, and the chairman for his leadership in this regard.

Thank you Mrs. Heckler. Is Ms. Drazen here?

STATEMENT OF MS. ERICA DRAZEN, MANAGER, HEALTH CARE UNIT, ARTHUR D. LITTLE, INC.

First, I'd like to tell a little bit about my experience, so you know the basis for my comments. I have been working in this area for about 12 years.

I have conducted formal evaluation of automated hospital information systems applications, mainly sponsored by the Federal Government. I have worked for private hospitals trying to help them make purchase decisions, and I have worked for commercial clients in market planning.

The thing that I think makes this experience somewhat unique is that I have had the advantage of seeing many systems being implemented. I have probably worked with about 200 to 300 individual clients in implementing hospital information systems. In my work for the Federal Government, I have also spent up to a year onsite in some locations, so I have some indepth experience as an outsider trying to observe the reasons for success and failure of information systems in a limited number—maybe 20 installations.

When I was thinking about this experience and what it could bring to bear on the subject today, I decided that there were three issues which were important to discuss. One is the reasons for success and failure of past information systems. Obviously, if there is a large amount of money being invested in a new system, we ought to try and make it as successful as possible, and I think there are lessons to be learned from the past.

Second is the steps that might be followed in planning for information systems. I am going to focus on the methodology that we have developed for the Department of Defense to help them plan for information systems for DOD hospitals.

And the third subject I would like to talk about is the state of information on costs and benefits of information systems.

REASONS FOR SUCCESS AND FAILURE

These are my observations based mainly on the indepth experimental studies that I have performed for the Federal Government. The first key factor that influences success and failure of an information system is the existence of a real need that is met by the system. Both of these things have to be present. There really has to be a need for the system, and the system has to be designed to meet that need.

This seems very obvious, but the reason for failure of about at least 50 percent of system failures, is the fact that the need for the system did not really exist. When need for the system really doesn't exist, it's very difficult to force potential users through the painful implementation process.

On the other hand, if the need for a system really does exist and users can be shown how the system will benefit them, they will do almost anything necessary to make the system work. I think that the difference in needs of different users is the reason that a system which is successful in one setting is a disaster in another setting.

When thinking about planning for coordinated health information systems for the United States, this problem of differences in needs of different users is going to be a tremendous issue to be faced. The first step in planning for an information system has to be a comprehensive needs assessment and users of the system must be involved in the planning and design phase in order for the system to be successful.

The second key issue, once you've got the ideal system, is existence of powerful, dedicated, advocates for the system within the facility or within the setting where it is being implemented. This is also a critical factor. Powerful, dedicated advocates are necessary in order to train people in the system use on a daily basis and work through the operational problems that are inherent in the implementation of any new system. This means that in planning for an information system, one has to consider how it can interface with existing systems, because current users of information systems are likely to be the most powerful advocates for any new system.

The third factor that influences success is technical performance of the system. Since people are depending on this system for their information needs, it is critical, of course, that it works whenever they need information, and in some applications, this means 24 hours a day, 365 days a year. Any system implementation plan must include a shakedown and phased testing of the system before it is ever implemented.

PLANNING FOR AN INFORMATION SYSTEM

I have already said that I think needs assessment is the critical step, and it's the first step. But in conducting a needs assessment, I think you have to be very careful. We can easily say we need better information on drug reactions; we need faster information on laboratory test results; we need more comprehensive information. But in order to plan for an information system, you need to know exactly what information is needed, and how quickly it is needed. In the example of the hospital lab test, if current turnaround time for lab tests is 24 hours and you really need it in 10 minutes, a system that will cut the turnaround time to 6 hours isn't going to buy you anything. I think the needs assessment process has to be done in quantitative terms in order to project realistic potential system benefits.

The second step in the planning process is to predict the potential benefits of the system using those quantitative information performance requirements.

And the third step is comparing costs and benefits. I'm not proposing that a formal cost/benefits study be done, but I think in order to set priorities among alternative systems or alternative applications, you need to know what the increase in effectiveness of information is going to be and compare that with what the increase in costs is going to be.

The fourth step is testing the system to insure that the technical performance is adequate. The last step is to evaluate the system in actual use.

STATUS OF INFORMATION ON COSTS AND BENEFITS OF SYSTEMS

Information on the actual costs and benefits of any information system application are sorely lacking. Most people do not retrospectively look at what the information system has done for them in a quantitative way.

In a recent study we did for the Federal Government, we looked at 200 articles about cost/benefits of information systems. We found about 20 that actually contained data rather than opinions, and about 6 of those were designed to provide a retrospective examination to determine what the costs and benefits of the system actually were. The others were just predictions of what the benefits were expected to be.

I think that it is critical to understand that when people talk about the benefits of automating information systems in health care, they are generally expressing their opinions: they are not reporting findings of research. I think there is a great misconception about the amount of data that is actually available to use as a basis for planning any future information systems.

In summary, I think that in a planning an information system, needs assessment is critical and users have to be involved in the planning process. There is a lot of experience with information systems, but there is also little data on which to base a plan for a new system. In order for any system to be politically feasible and to be operationally effective, it has to interface with existing systems, since current users could potentially be the best advocates for any new information system.

Thank you.

[The prepared statement of Ms. Drazen follows:]

PLANNING FOR A COORDINATED HEALTH INFORMATION SYSTEM

Testimony by Erica Drazen

June 4, 1981

I am pleased to be here today to discuss planning and policy issues related to development of a Coordinated Health Information System (CHIS). First, I would like to briefly describe my experience in the area in order for you to understand the basis for my comments. For the last twelve years I have participated in planning for information systems to support health care delivery. Most of my early research work, which was sponsored by the National Center for Health Services Research, involved documenting the costs and care delivery changes resulting from implementation of clinical medical information systems; for example, computer-based patient monitoring systems and computer-assisted ECG analysis systems. These studies involved on-site data collection and observation throughout the planning and implementation process as well as when systems were in routine use. Therefore, I was able to assess quantitative measures of system benefits and gain qualitative information on use of the system.

I have also assisted hospitals and private industry in planning for automation within the health care environment and currently I am conducting evaluations of the costs and benefits of medical information systems for the Department of Defense. The DOD is using information from these evaluations to design information systems to improve effectiveness and economy of health care within DOD hospitals.

I have considered what findings from my research would be most relevant to present at these meetings, and I have decided to discuss three rather separate issues:

1. Factors determiniqg success of failure of a medical information system.
2. Steps which might be followed in planning for a coordinated health information system.
3. Key issues to consider early in the planning process.

FACTORS AFFECTING SUCCESS OR FAILURE OF A MEDICAL INFORMATION SYSTEM

The development of a National Coordinated Health Information System would be a major undertaking, involving a large commitment of funds; obviously it is imperative to determine in advance whether such a system is likely to succeed or fail. By "succeed" I am referring to success from only a user's perspective--whether the system is operational, and valued by the users. Later I will discuss a higher level measure of success--whether the system's benefits are worth the associated costs.

Some medical information systems currently in use are considered successful by their users. They are in routine use, are supported by the staff, users are willing to pay for the systems, and users are unwilling to give them up. However, there are certainly a large number of systems which clearly have been unsuccessful; they have never come into routine use and are now rarely used or have actually been removed. Many system implementations obviously would be classified as "somewhat successful". I, and many others, have observed the same information system being highly valued in one setting and never used in another. Therefore, during my research I have tried to isolate factors which have led to success or failure of automated information systems. These factors shown in Table 1 are described in more detail in other documents.[1] I will discuss only the key success factors relevant to the success or failure of the system being discussed today.

The most important determinant of success is Existence of a Real Need for the system. If the system is not needed, if it doesn't offer users tangible benefits which they can see and value, potential users will not be motivated to learn to use a new system, will be intolerant of inevitable start-up problems, and will almost always reject the system. Conversely, a system which meets a real need will almost always be used even if substantial user training and change in practice is required. In my experience, when a system failure is blamed on people being unwilling to learn to use the system, the real failure is that the system did not provide potential users with enough benefits to be worth the time and effort required to learn and use the system. Existence of a real need is the most important factor influencing success or failure of any information system. Differences in the needs of different users is one common reason a system which was successful in one location, will not be successfully transferred to another facility. Therefore a needs assessment is the most critical step in planning for a medical information system.. It is also typically the most neglected part of the planning process and therefore, there is little past experience to draw upon in planning for a CHIS.

A second important factor is Design or Selection of a System to Meet the Existing Need. Obviously, unless existing needs are met by the information system, the system will not be valued. In most cases, this means that the medical information system must be modular to be able to be tailored to each facility, and must be able to be changed in the future as user's needs change.

If an appropriate system is available, the existence of a powerful, dedicated advocate for the system is the next determinant of success. Implementations of automated information systems almost always encounter technical or operational problems which must be overcome as soon as possible. Implementation also involves training potential (and perhaps skeptical) users on how to interface with the system and how to derive benefits from its use. Without a powerful dedicated advocate, it is difficult to manage a smooth transition from a manual to automated system, and to achieve maximum benefits from the system's use.

System advocates are almost always available when an idea for an automated system comes from the ultimate user. This would indicate that a CHIS plan which fosters local initiatives and tries to enhance the utility of existing information systems will be more successful than one which involves inventing and then selling a new (replacement) system.

The last key determinant of success is technical performance of the system. Users are naturally wary *of trusting critical information to* a computer-based information system which might be "down" when they need access to the stored data. Yet maintaining an automated and manual system in parallel is costly and frustrating. Unless the system works well early in the implementation and is almost always available when needed, users will not give up their manual records and will soon abandon the redundant automated system.

In contemplating a development of a CHIS, design and phasing of system trials to identify and correct technical and operational problems must be considered.

STEPS TO BE FOLLOWED IN PLANNING FOR A CHIS

Table 2 shows steps in the planning process that we are using in some of our current HIS planning for the DOD. I will discuss the most important element of the process.

Determining Need

As mentioned in the previous discussion, I feel that existence of a real need which will be met by the system is critical to the success of an information system. Therefore, needs assessment is a logical first step in planning for a CHIS. To be useful in planning for a system, needs must be defined in quantitative terms and in a way which reflects the true information requirements of the application.

For example, a statement that information on work place exposure needs to be integrated with hospital medical records must be examined to determine:

- what information is available on the work environment now
- what would be valuable in treating patients outside the work place
- how quickly is the information needed
- which segment of the population would receive most benefit
- what geographic area would need to be covered

A statement that we need better access to laboratory data to monitor use of new drugs needs to be translated to:

- How quickly is laboratory data needed--within 5 minutes, 5 hours, 5 days?
- How long must these data be stored--for 1 day, 5 days, for the duration of one treatment episode?

- What other clinical information must be correlated with the laboratory data?

Predicting Benefits

The next step in the planning process involves evaluating performance of the current system and the proposed new information system against the requirements established in the needs assessment. If laboratory data are needed in 5 minutes and are now available in 5 hours, can an information system be designed to effect a significant change (to 5 minutes or under)?

This step of the planning process, where feasibility of introducing meaningful changes in the performance of the current information system are examined is critical to identifying and evaluating potential system benefits. In the case of laboratory data cited earlier, a 50% improvement in timeliness of results--from 5 hours to 2 1/2 hours--would be useless if results were needed in 5 minutes.

Prediction and evaluation of potential benefits against performance criteria must be completed for every potential application of an information system as part of the system planning process.

Relating of Costs to Benefits

Performing a rigorous cost benefit analysis where all important benefits of the system are valued in dollars and compared to system costs is probably not appropriate or valuable in the early planning of a CHIS. However, a comparison of differences in costs between manual and automated modes of operation with differences in benefits of manual and automated systems can be useful in prioritizing projects or screening for likely "winners" or "loosers". An application predicted to increase operational costs by 10% and improve effectiveness of services by 50% would most likely receive priority over a system which would result in a 50% increase in costs and a 10% increase in effectiveness of services.

Sponsoring Field Trials

Despite extensive planning efforts and attention to accurate and meaningful prediction of benefits, actual use of the system and documentation of realized benefits is critical to design of an effective automated information system. The field trials also provide information on likely implementation issues and critical factors influencing success of the system as well as identify changes in the system which would improve its performance, enhance benefits or decrease costs.

I feel it is essential to keep in mind that although many people assert that computer systems will control costs of medical care by detecting errors, preventing duplicate services, increasing access to information and enhancing medical research, they are usually expressing opinions, not relating documented changes which have occurred. I do not claim that the assertion that automation of the health care system will be cost effective is untrue. In fact, I believe that the many computer applications will be shown to be cost effective. However, documentation and valuing of the system's actual impacts, benefits, and costs is lacking despite extensive experience in use of health information systems. NCHSR sponsored a study to identify evaluations of cost-benefits of automated information systems.[2] Although over 200 papers or research reports were identified which discussed costs and benefits of automation, most of these contained only the opinions of the users on the system's value. Less than twenty studies contained data on system costs or benefits and most of these studies only went as far as predicting benefits of the system.[3-14] No study was identified which attempted to value all the major impacts of the information system.

Evaluation of the costs and benefits of potential functions of a CHIS will have to be included in the planning process. One group that has begun to systematically document costs and benefits of medical automation is the TRIMIS Program Office of the DOD. Their experience may be very valuable in planning for a CHIS.

KEY ISSUES IN PLANNING FOR A CHIS

There are four issues which I feel are most important in planning for a CHIS.

1. Needs Assessments - Identification of System Advocates and Evaluation of Costs and Benefits of Potential System Applications are the key steps in planning for a medical information system.

2. There is little data on utilization and costs and benefits of existing automated information systems which can be used in planning a CHIS.

3. There is a great deal of experience in implementation and use of automated information systems which could provide a basis for initial planning of a CHIS.

4. Any CHIS will have to be designed to interface with or accommodate existing information systems since many of these systems are highly valued by their users, who could be strong advocates and users of a Coordinated Health Information System.

Table 1

Factors Influencing Success of Information Systems

Existence of a Real Need

Design of a System to Meet the Need

Presence of a Powerful, Dedicated Advocate

Compatibility with Existing System

Initial System Reliability

Effective Training of Users

Uniformity of System Requirements

Table 2

Steps in Planning a Medical Information System

1. Review Available Systems
2. Review Needs
3. Develop Performance Requirements
4. Assess Performance of Current System
5. Predict Performance of Proposed System
6. Plan Field Trials
7. Develop Concurrent Evaluation Plan
8. Collect Baseline Data
9. Install Trial System
10. Test Performance of System as Installed
11. Monitor Implementation, Modify System
12. Collect Data After Implementation
13. Analyze Costs and Benefits of Trial System
14. Recommend System Changes to Increase Benefits or Decrease Costs
15. Predict Costs and Benefits of Future Systems

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Mr. **Brown**. Thank you very much, Ms. Drazen.

I have noted over the last 7 years that Arthur D. Little is involved in a number of matters involving information systems and more specifically in the field of scientific and technological information, and I refer to a report they made to us 3 years ago—maybe longer than that now. The last major report that I recall on scientific and technological information systems suggested the need for a broader concept of scientific, technological, and societal information and to develop a very broad conceptual framework for this, which impressed me.

I wanted to just inquire if your work in hospital information systems or health information systems by any chance is part of a larger framework involving the concept of scientific, technological, and societal information?

Ms. **Drazen**. No; it really isn't, and I'm unfamiliar with the report that you're referring to.

I can assume that that report came from our information systems division, who are technically oriented, and my experiences are more user-based.

Mr. **Brown**. It's your experience we're looking for. May I ask Ms. Schneider if she has any questions this morning?

Ms. **Schneider**. I'd like to know if it's possible to network some of the existing hospital information systems into a coordinated system.

Ms. **Drazen**. I think it's possible, and there have been some attempts to do that. Some of them have been successful. One problem in networking is that there is an interface problem. No one is really responsible for trying to interface systems, and vendors are reluctant to interface with other companies' equipment. So there is a political issue.

I think in most cases it's technically feasible, although I have encountered cases where it wasn't technically feasible to interface two systems that a client had wanted to interface.

Ms. **Schneider**. What kind of impetus might you recommend from the Federal Government?

Ms. **Drazen**. Well, I think there really is a need for developing standards, and I don't see who else is going to do it. We have been talking about standards in this business for a long time, and we haven't gotten anywhere as far as I can see. I think that really there has to be some kind of a major effort in standards development.

Ms. **Schneider**. Could I just have your impression of the need for a global networking system?

Ms. **Drazen**. It's conceptually very attractive. But being an engineer by training, I think in quantitative terms, and I don't think we have the data to really project what the benefits of such a system would be and whether it would be worth the cost. There is some limited experience in developing networks like the SEARCH system in Rhode Island, for instance, and the Department of Defense has been doing some work, and there has been some other civilian work. Other countries are also working in this area. Japan is trying to develop a national network for Japan. Although there has been some experience worth developing integrated information systems no one has really looked at the costs and benefits of these systems, I really could not make a judgment on whether or not we should extend them.

Ms. **SCHNEIDER**. Thank you very much. Thank you, Mr. Chairman.

Mr. **BROWN**. Thank you, Ms. Schneider.

Mr. Scheuer?

Mr. **SCHEUER**. Thank you, Mr. Chairman.

We appreciate your testimony very much. I am a little concerned that you say that planning for a CHIS requires a powerful, dedicated advocate. Now most of us are not powerful, except for the chairman. Few of us are dedicated, and most of us aren't very good advocates of anything. We go our way, and we aren't terribly articulate. Once in awhile, you see a noble experiment that succeeds based on the extraordinary qualities of leadership of one individual, and whatever it is may work very, very well.

Martin Luther King may have done something in Birmingham that succeeded because of his extraordinary qualities of magnetism and leadership. You couldn't extrapolate that infinitely, if these unique qualities weren't there.

If in every one of these 7,000 hospitals around the country you need a powerful, dedicated advocate, I get the signal that we're not going to move very fast into a comprehensive health information system, if it requires all of that unusual talent to lead each hospital into the promised land. What you're telling me is that the impediments and the inertia and the bruised egos are going to prevail most of the time after this combination of powerful advocacy and dedication.

Ms. **DRAZEN**. My experience is that if a system can be designed that meets the existing needs of a user, then you can easily develop a powerful advocate. The problem comes when you try to impose a system on users which they didn't recognize a need for. Then a powerful advocate for the system is almost never around, and the success is unlikely. Potential users have to be involved in the planning process, and then the system that evolves will probably meet their needs, and they will be powerful advocates for the system.

Powerful advocates in implementing information systems are people who control the information process, use the information that is being automated. They do not have to be powerful in other terms. If you can convert them to be advocates, which you can do by meeting their needs, then I don't think you will have a problem.

Mr. **SCHEUER**. The question is, who is going to decide what the needs are? If I had been working in a certain environment with very little medical information available, I'm used to that. And if I'm asked what would be valuable in treating patients in addition to what I have, I would say, "Well, you know, we're getting along fine here, sir." As to how quickly the information is needed and how quickly the lab data is needed, generally people tend to be satisfied with what is.

Ms. **DRAZEN**. That hasn't been my experience.

Mr. **SCHEUER**. If they weren't satisfied with what is, why is it that out of 7,000 hospitals in this country, we only have approximately 30 of them with what you would characterize as a truly comprehensive health information service? Why has the progress been at such a snail-like pace?

If the decisionmakers at each of these hospitals were ready and eager to reach out and bring in new systems, that would make more information available to them in the workplace. As you characterize it, we give them laboratory information virtually within minutes or instantaneously. Why, since we had the last set of hearings on this identical subject 3 or 4 years ago, has there been such a glacial rate of progress?

Ms. **Drazen**. I think there are several reasons for that. One is that probably some of the systems out there really do not meet the needs of users. They really don't do what you just said they do—provide information quicker.

Mr. **Scheuer**. In other words, they weren't really well-designed systems.

Ms. **Drazen**. Yes; I think that's right. They weren't designed to meet a lot of the existing needs of the users.

If you look at another system, automated ECG services, which are available on a network basis, both regionally and nationally, you will find that 40 percent of all hospitals under 100 beds, the hospitals that generally do not have expert cardiologists on their staff, use automated analysis of electrocardiograms. That has happened over the last 10 years. This is an example of a system that meets a clearly defined need of the user. It's available in a cost-effective way from several vendors, and its diffusion has been very rapid.

Mr. **Scheuer**. What does that system do?

Ms. **Drazen**. Users transmit an electrocardiogram over phone lines. It's analyzed by computer, and then the results are transmitted back to the user within 15 or 30 minutes.

Mr. **Scheuer**. While the patient waits in the office?

Ms. **Drazen**. It can be while the patient waits in the office or in the emergency room.

It isn't necessarily true that everything has gone at a snail's pace. You're right—total hospital information systems have gone at a snail's pace. I think that's indicative of the fact that maybe there's something wrong with the solution that's being proposed. Maybe there really isn't the need for it then. Maybe they are "overkill" systems. Maybe what is needed is a lab system and a pharmacy system which wouldn't cost as much as a total hospital information system.

Mr. **Scheuer**. In other testimony, the day before yesterday, you said about what a great assistance it is in the process of diagnosis to have a computer data bank available to sort out millions or even billions of pieces of information immediately available in diagnosing the patient. Now if that's true, wouldn't you say that every doctor in every hospital in the United States ought to have a computer-assisted diagnostic capability? If it's true that at 30 hospitals, physicians have been able substantially to increase the sophistication and the accuracy of their diagnostic capability, why then can you not postulate as a given that any physician anywhere will do a better job of diagnosis, if he has this computer assistance at his elbow?

When then should you accept it as a matter of politics and increasing acceptability? Why should you as a matter of substantive decisionmaking, have to ask the physcians at a particular hospital, do you think you need—as compared to all of these other hospitals, where they have a clear need and benefited by it—do you think you need a computer-based aid to their diagnostic capability?

In other words, once you have established through 30 hospitals, as you have now, or 60 or 100 that even the best-trained doctor doesn't have the memory of the computer, many extraordinarily talented doctors have found in experience that a computer-based diagnostic aid is of enormous help to them. Once you have established that as a given, why should every set of decisionmakers, every power broker—talking about doctors as a group in every hospital—be consulted as to whether they perceive they have a need.

Ms. **DRAZEN**. I don't think that would be reasonable. I wouldn't expect that every doctor in every hospital would be asked to determine whether or not they have a need for the system. I think if 30 hospitals representing the range of kinds of hospitals in the country documented there is a real need for the system and benefit from it, I would say that's an adequate needs assessment.

Mr. **SCHEUER**. Then couldn't you devise several lists? One list of things that experience up to now has proven that no matter what region, no matter what the level of sophistication of health care, be it a tertiary hospital, a community hospital, a nursing home. No matter whether rural or urban, east or west, north or south, a list of half a dozen?

Ms. **DRAZEN**. I think you can.

Mr. **SCHEUER**. That they should be made almost as available as a given. And there may be other aspects of a CHIS that would be region-dependent and type of care-dependent and type of patient dependent, and that would fluctuate region by region.

Ms. **DRAZEN**. I think you can make several lists. You can make lists of the applications which are pretty well established, where there are many users and which look like clear winners although there aren't data available to document these costs and benefits.

Mr. **SCHEUER**. Clear winners and should be universally applied.

Ms. **DRAZEN**. And then you can make a list of applications where there has been experience, but equivocal results. This list would also include applications where there is experience in tertiary hospitals, but you don't know how applicable that is in the rest of the world. Those are the ones you want to look at critically. And then there are these others which we don't have much experience with.

I think the problem is that among all those clear winners, it's very hard to set priorities, because nobody knows how much you're winning for what dollars among those applications. This is why you really have to examine things in terms of cost/benefit, in order to decide, should our first priority be a network of pharmacy systems across the United States, or should first implement decision support systems, or should we sponsor automated ECG systems, or lab information systems, or integrating work place environment data into health records? The list is long. You have to look what the priorities might be.

Mr. **Scheuer**. Ms. Drazen, if each one of those are justifiable on its merits as being cost-beneficial, why do they have to compete each with the other?

Ms. **Drazen**. They aren't justified on cost-benefit. Has anyone looked at what the cost-benefit of each system versus building a medical library next door or versus having, 25 more physicians? I don't think that data exists. I don't think people know what cost-benefit of putting an integrated pharmacy information system in a community is. That's a poor example. Since, there's probably more data on pharmacy than anything else. But I don't think that people have information on the costs and benefits of a lot of these applications.

Mr. **Scheuer**. Well, maybe you're saying that it's probably just as well we haven't moved too fast, because if we had moved a great deal faster than we have, we may have moved into areas where substantial costs would have accrued, with not very impressive benefits. Probably a go-slow process with more acute and more focused attention to the costs and the rewards of each of these processes would be well justified.

Ms. **Drazen**. I think that's true, I think one of the reasons the systems have moved slowly in most cases is that they are quite expensive and the decisions to purchase involve administrators as well as clinicians, and also sometimes health planners. When you look at these multiple perspectives, issues are raised as to what the cost-benefit of the system really is. People aren't willing to make the massive investments when they have doubts about what the system is going to accomplish.

Mr. **Scheuer**. In other words, you're saying this isn't a question of ego or inertia; it's a question of sincere and well-conceived reservations, let's say.

Ms. **Drazen**. I think so.

Mr. **Schfuer**. All right. What kind of process should the Congress be encouraging to accelerate the pace with which we are examining each of these component elements and come up with some yardsticks or guidelines as to whether each one of them under a certain set of circumstances, certain medical health environment, would the cost be justified by the benefits to be accrued? How do we systematically move ahead?

Ms. **Drazen**. Well, I think that's really the critical issue and, as I mentioned in the testimony, very few people are motivated to look at the cost-benefits of the system, once they buy it.

Mr. **Scheuer**. The point is, individual people can't look at cost benefits. This is a very sophisticated process. It needs real expertise and in itself a good deal of resourses. But the payoff, if you can apply cost-benefit analyses to these components of the system, that might well one day be made universal, the advantage of having that investment in cost-benefit analysis would be very great indeed. What is the system for doing that?

Ms. **Drazen**. Many of these systems were developed with Federal Government moneys, and one thing that could be done is to make a contingency that the Federal Government moneys can not only be spent developing systems that are going to be later evaluated. There might be a way to tie it into the health planning process, if that's going to exist. There are some people—and I think you are going to be hearing from the TRIMIS program—who have integrated evaluation as a specific component of their planning process. I think that we can learn a lot from their experience, since they are gathering evaluative data as a part of their planning process. If you want to know the cost/benefit of the systems, it's reasonable to invest a fraction of the moneys that have been invested in the developing systems in evaluating what their costs and benefits really are. This just hasn't been done to date in any large-scale way.

Mr. SCHEUER. In order to do this, do you think we can rely on a voluntary system of gathering data, or must it be mandated?

Mr. OLDAKER. There's so little incentive from the end-user point of view to do, unless they're thinking of rebuying, repurchasing a system, that——

Mr. SCHEUER. Once they've got it, they've got it.

Ms. DRAZEN. They've got it. They're going to live with with it, they have paid for it. They will devote their energy into trying to make it better. I don't think it's reasonable to expect that they're going to devote their energy getting information that would only be useful to someone else.

Mr. SCHEUER. Thank you. Mr. Chairman, the witness is extremely stimulating and thoughtful, and I could go on for hours with her.

Mr. BROWN. I was hoping you wouldn't. [Laughter.]

Thank you very much.

Mr. Walgren?

Mr. WALGREN. No questions, Mr. Chairman.

Mr. BROWN. Mr. Gregg?

Mr. GREGG. No questions, Mr. Chairman.

Mr. BROWN. Mr. Shamansky?

Mr. SHAMANSKY. No questions, Mr. Chairman.

Mr. BROWN. Thank you very much.

I'd like to have Dr. Siegel, Administrator, Chemical Substances, Information Network, and Colonel McGinnis and Colonel Bickel all come up to the table, if they would. It will just save us a little time.

STATEMENTS OF DR. SIDNEY SIEGEL, ADMINISTRATOR, CHEMICAL SUBSTANCES INFORMATION NETWORK, U.S. ENVIRONMENTAL PROTECTION AGENCY; COL. JOHN W. McGINNIS AND COL. RUDOLPH G. BICKEL, TRI-SERVICE MEDICAL INFORMATION SYSTEMS PROGRAM OFFICE, DEPARTMENT OF DEFENSE

Mr. BROWN. Dr. Siegel is going to tell us, presumably, about the Chemical Substance Information Network, and Colonels McGinnis and Bickel about the TRIMIS. The two are not necessarily related, but we will have Dr. Siegel proceed first, if you will, and then have some questioning of him and then Colonel McGinnis and Colonel Bickel, and then we will ask them about the TRIMIS system.

Dr. Siegel, we are very pleased to have you here this morning. We recognize the importance of the Chemical Substance Information Network and, in a sense, hope that it can serve at least in part a model for complex information networks, one of the things we are very much interested in.

Please proceed with your testimony.

Dr. SIEGEL. Sir, I would like to talk about a noble experiment this morning. I have been asked to describe the efforts which have gone so far gone into the planning and development of the Chemical Substances Information Network, CSIN, and comment on whether this experience could be useful as a model for a Coordinated Health Information System, CHIS.

This is best accomplished by describing some of the administrative mandate given to the Environmental Protection Agency and how this was translated into the technology described as CSIN.

When the Toxics Substances Control Act, TSCA, was passed in 1976, it became part of an array of federal laws under which government agencies are required to collect data and information about many aspects of chemical substances. An analysis done at that time identified over 200 data and information resources that were supporting numerous agencies in the performance of their legal mandates. The needs and requirements of each agency and program were reflected in the design and operational modes of these individual resources. These resources often contain specialized information which may duplicate what is needed and gathered by another organization. One significant impact of TSCA is that even more dimensions of data and information relevant to the effect of chemical substances on human health and the environment are required not only by government but also by industry and academia.

Sections 10 and 25(b) of TSCA direct EPA, with the help of the Council on Environment Quality, to coordinate the support of other government agencies, and also to solicit and coordinate the involvement of other communties interested in chemical substances, in studies concerning the feasibility of establishing: (1) Standard classification schemes for chemical and related substances; and (2) means to store, identify and access information with respect to such substances. EPA, with support from all the communities, is also to coordinate the development and maintenance of computerized resources which can efficiently and effectively identify, access, retrieve and aid in the analyses of biological and chemical data in ways which are responsive to the purposes of TSCA and similarly oriented legislation.

Data and information technology generated through such efforts is to be made available to all interested communities. To fund and support such efforts the Interagency Toxics Substances Data Committee, ITSDC, was established as a permanent mechanism in February 1978. Membership presently consists of some 25 departments, agencies and programs of government. The ITSDC, in order to respond to these complex and interrelated technical and administrative issues, established a CSIN Subcommittee to guide the development of responses to the studies required and the technical capabilities identified as needed in sections 10 and 25(b) of TSCA. EPA, with the concurrence of the ITSDC and its CSIN Subcommittee, established an Office of Network Administration within the Office of Toxics Integration. Network Adminstration has the day-to-day responsibilities for planning, issue identification and resolution, implementation and operations.

My chief, Dr. Marilyn C. Bracken, who is Associate Assistant Administrator for Toxics Integration in EPA, had previously prepared a report which surveyed how existing information resources were being used and also identified user community needs which were not being adequately served. More requirements analysis followed, which addressed various aspects of this problem. These studies identified in detail the data and information needs of the communities being impacted by TSCA and similar legislation.

The needs include information about chemical substances such as identification, economics, production levels, production processes and associated technology, epidemiology, environmental fate, applicable standards and regulations. It was further determined that these categories of information were needed by organizations with functional responsibilities to do research and development, generate decision packages for management, evolve risk or cost-benefit analysis, and prepare or interpret regulations and guidelines.

The CSIN Subcommittee with support from Network Administration reviewed the various studies to identify user requirements, as well as the capabilities and potential of various computer technologies to meet the needs of many kinds of communities. The subcommittee concurred with the recommendations of Network Administration and proposed to the ITSDC that the best method of providing the large volumes of diverse and disparate data and information needed by a broad spectrum of user communities, each with unique requirements, was to blend two computer technologies into a CSIN. The technologies were networking and distributed data base management as an intermediary system. The approach was accepted by the ITSDC and the combined technologies have now gone through two stages of design and implementation.

Stage 1 or preprototype CSIN is based on an intelligent terminal, and stage 2, or prototype CSIN, uses a stand-alone minicomputer to manage user access to various computerized data and information resources. The prototype CSIN is presently being tested. Prototype CSIN is capable of managing user access to and use of resources which are independent and autonomous of each other. These resources are scattered geographically, have heterogenous computer hardware and software environments, and are diverse for their data and information content. The user of CSIN, when the prototype becomes operational, will not need to be knowledgeable about aspects of an information resource such as: connect and log-on procedures; syntax; record format requirements; and the search strategies or logical arguments required to establish and process queries through a system's unique command language.

Independent computer scientists had reviewed the technology presently being implemented to support CSIN. These scientists feel that in CSIN we are logically extending the capability of distributed data-base management which was first implemented for the Department of Defense. They have commented further that while implementation and maintenance of a CSIN is not technically trivial, it is feasible and within the capabilities of the present state of the art of computer science. These consultants believe the issues which will prove most difficult to identify, scope out, and resolve will be administrative, economic, legal, and political. They have been proven correct.

While the technology supporting CSIN has been demonstrated to be workable and useful, there are some startup problems in the software controlling the management computer. These problems seem to be addressable, and we plan to have an experimental version of the prototype CSIN operational in the fall of this year.

The technical and administrative issues that have been identified and, in part addressed for CSIN will most likely parallel the analysis of needs, identification, and resolution of issues prior to the planning and implementation of a cost-effective coordinated health information system.

Of special pertinence to the CHIS project would be the experience we have gained in the following issues: technology; administrative and legal relationships with owners or managers of independent resources; confidentiality and the appropriate sharing of data; data rights; copyrights; data quality; and use of mathemetical modeling or correlation techniques in a network environment.

In summary, the combined technology of networking and intermediary system offers managers and planners more options for the selection of the most cost-effective paths to develop and to maintain access to data and information required for decisionmaking at all organizational levels.

[The prepared statement of Dr. Siegel follows:]

STATEMENT OF
DR. SIDNEY SIEGEL
ADMINISTRATOR, CHEMICAL SUBSTANCES
INFORMATION NETWORK
OFFICE OF TOXICS INTEGRATION
U.S. ENVIRONMENTAL PROTECTION AGENCY
BEFORE THE
SUBCOMMITTEE ON SCIENCE, RESEARCH, AND TECHNOLOGY
AND THE
SUBCOMMITTEE ON NATURAL RESOURCES, AGRICULTURE RESEARCH AND ENVIRONMENT
OF THE
COMMITTEE ON SCIENCE AND TECHNOLOGY
U.S. HOUSE OF REPRESENTATIVES
JUNE 4, 1981

I have been asked to describe the experience gained from efforts which have so far gone into the planning and development of the Chemical Substances Information Network (CSIN) and comment on whether this experience could be useful as a model for a Coordinated Health Information System (CHIS).

This is best accomplished by describing some of the administrative mandate given to the Environmental Protection Agency and how this was translated into the technology described as CSIN.

When the Toxics Substances Control Act (TSCA) was passed in 1976, it became part of an array of Federal laws under which government agencies are required to collect data and information about many aspects of chemical substances. An analysis done at that time identified over 200 data and information resources that were supporting numerous agencies in the performance of their legal mandates. The needs and requirements of each agency and program were reflected in the design and operational modes of these individual resources. These resources often contain specialized information which may duplicate what is needed and gathered by another organization. One significant impact of TSCA is that even more dimensions of data and information relevant to the effect of chemical substances on human health and the environment are required not only by government but also by industry and academia.

Sections 10 and 25(b) of TSCA direct EPA, with the help of the Council on Environment Quality, to coordinate the support of other government agencies, and also to solicit and coordinate the involvement of other communities interested in chemical substances, in studies concerning the feasibility of establishing: (1) standard classification schemes for chemical and related substances; and (2) means to store, identify and access information with respect to such substances. EPA, with support from all the communities, is also to coordinate the development and maintenance of computerized resources which can efficiently and effectively identify, access, retrieve and aid in the analyses of biological and chemical data in ways which are responsive to the purposes of TSCA and similarly oriented legislation.

Data and information technology generated through such efforts is to be made available to all interested communities. To fund and support such efforts the Interagency Toxics Substances Data Committee (ITSDC) was established as a permanent mechanism in February 1978. Membership presently consists of some 25 departments, agencies and programs of government. The ITSDC, in order to respond to these complex and inter-related technical and administrative issues, established a CSIN-Subcommittee to guide the development of responses to the studies required and the technical capabilities identified as needed in sections 10 and 25(b) of TSCA. EPA, with the concurrence of the ITSDC and its CSIN-Subcommittee, established an Office of Network Administration within the Office of Toxics Integration. Network Administration has the day to day responsibilities for planning, issue identification and resolution, implementation and operations.

My chief, Dr. Marilyn C. Bracken, who is Associate Assistant Administrator for Toxics Integration in EPA, had previously prepared a report which surveyed how existing information resources were being used and also identified user communtiy needs which were not being adequately served. More requirements analysis followed, which addressed various aspects of this problem. These studies identified in detail the data and information needs of the communities being impacted by TSCA and similar legislation. The needs include information about chemical substances such as identification, economics, production levels, production processes and associated technology, epidemiology, environmental fate, applicable standards and regulations. It was further determined that these categories of information were needed by organizations with functional responsibilities to do research and development, generate decision packages for management, evolve risk or cost benefit analysis, and prepare or interpret regulations and guidelines.

The CSIN-Subcommittee with support from Network Administration reviewed the various studies to identify user requirements as well as the capabilities and potential of various computer technologies to meet the needs of many kinds of communities. The Subcommittee concurred with the recommendations of Network Administration and proposed to the ITSDC that the best method of providing the large volumes of diverse and disparate data and information needed by a broad spectrum of user communities (each with unique requirements) was to blend two computer technologies into a CSIN. The technologies were networking and distributed data base management as an intermediary system. The approach was accepted by the ITSDC and the combined technologies have now gone through two stages of design and implementation.

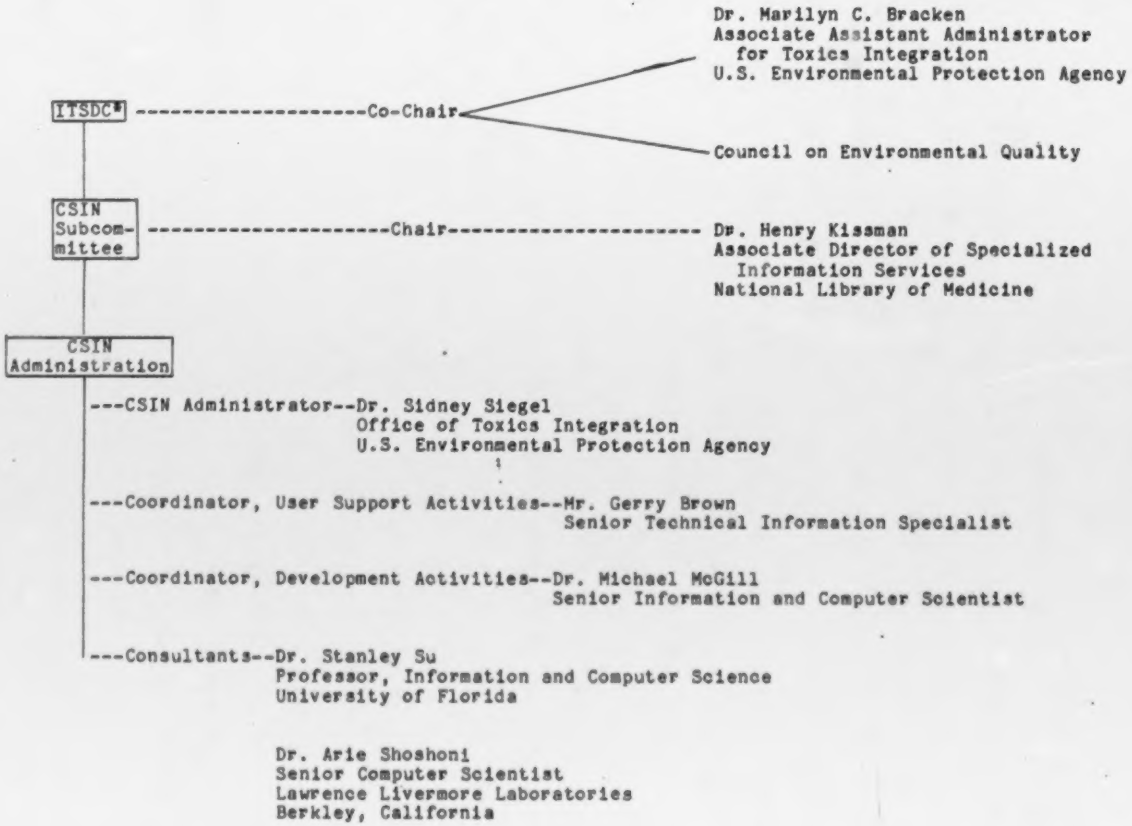
Stage one or Preprototype CSIN is based on an intelligent terminal, and stage two, or Prototype CSIN, uses a stand alone mini-computer to manage user access to various computerized data and information resources. The Prototype CSIN is presently being tested. Prototype CSIN is capable of managing user access to and use of resources which are independent and autonomous of each other. These resources are scattered geographically, have heterogenous computer hardware and software environments, and are diverse for their data and information content. The user of CSIN, when the prototype becomes operational, will not need to be knowledgeable about aspects of an information resource such as: connect and log-on procedures; syntax; record format requirements; and the search strategies (logical arguments) required to establish and process queries through a system's unique command language.

Independent computer scientists have reviewed the technology presently being implemented to support CSIN. These scientists feel that in CSIN we are logically extending the capability of distributed data base management which was first implemented for the Department of Defense. They have commented further that while implementation and maintenance of a CSIN is not technically trivial, it is feasible and within the capabilities of the present state of the art of computer science. These consultants believe the issues which will prove most difficult to identify, scope out and resolve will be administrative, economic, legal, and political. They have been proven correct.

While the technology supporting CSIN has been demonstrated to be workable and useful, there are some start-up problems in the software controlling the management computer. These problems seem to be addressable and we plan to have an experimental version of the Prototype CSIN operational in the fall of this year.

The technical and administrative issues that have been identified and, in part, addressed for CSIN will most likely parallel the analysis of needs, identification and resolution of issues prior to the planning and implementation of a cost-effective "Coordinated Health Information System." Of special pertinence to the CHIS project would be the experience we have gained on the following issues: technology; administrative and legal relationships with owners or managers of independent resources; confidentiality and the appropriate sharing of data; data rights; copyrights; data quality; and use of mathematical modeling or correlation techniques in a network environment.

In summary, the combined technology of networking and intermediary system offers managers and planners more options for the selection of the most cost-effective paths to develop and to maintain access to data and information required for decisionmaking at all organizational levels.



ITSDC* ----------------Co-Chair

Dr. Marilyn C. Bracken
Associate Assistant Administrator
for Toxics Integration
U.S. Environmental Protection Agency

Council on Environmental Quality

CSIN Subcommittee ----------------Chair---------------- Dr. Henry Kissman
Associate Director of Specialized
Information Services
National Library of Medicine

CSIN Administration

---CSIN Administrator--Dr. Sidney Siegel
Office of Toxics Integration
U.S. Environmental Protection Agency

---Coordinator, User Support Activities--Mr. Gerry Brown
Senior Technical Information Specialist

---Coordinator, Development Activities--Dr. Michael McGill
Senior Information and Computer Scientist

---Consultants--Dr. Stanley Su
Professor, Information and Computer Science
University of Florida

Dr. Arie Shoshoni
Senior Computer Scientist
Lawrence Livermore Laboratories
Berkley, California

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* Interagency Toxic Substances Data Committee

An Overview of the Chemical Substances Information Network

June 1, 1981

The CSIN concept was proposed as a means of satisfying the Toxic Substances Control Act (TSCA) and similarly oriented legislation. The network presently in development will provide methodology to efficiently and effectively identify, access and use data and information in diverse information resources. It is to serve the needs of administrators, engineers and scientists in the private sector, academia, and government with responsibilities concerning the development, production, use, environmental fate, regulation, and other aspects of chemical substances. In order to meet these needs, it will offer access to, and the processing of, data and information on chemicals concerning their nomenclature, molecular structure, physical-chemical properties, toxicology, production, control technology, economics, uses, and regulations and guidelines.

CSIN is a new type of data and information resource -- not simply another computerized data base into which data from many sources would be gathered, reformatted, reorganized and then would become available. It is a network that will be capable of offering access to and coordinating the use of autonomous and independently owned and operated resources. In so doing, CSIN offers to users more data, information and processing capability than any one resource could provide.

A communications network combined with an intermediary (switching) system is used to link or provide access to computerized information resources where material relevant to chemical substances is available. CSIN will not only link to independent resources, it will also integrate them into coherent problem-solving tools while the resources maintain their administrative and operating independence and autonomy The computer technology described as distributed data base management supports user access to a CSIN by providing an intermediary or switching system with facilities capable of coordinating the use of independent information resources. CSIN further will offer options to users as to their level of interaction with individual systems.

The need for a network oriented toward chemical information arises from the diversity of data and information needs, relevant to chemical substances, of many different kinds of communities. For example, to establish the usefulness of substitutes for a particular chemical substance, it may be necessary to gather the following kinds of information:

(a) Identification of all synonyms, Chemical Abstracts Services (CAS) registration numbers and other identifiers for the original substance and for each potential substitute. These will aid in the identification of data and information on chemicals of interest in subsequent searches.

(b) Locating and accessing data on the physical-chemical properties of the original chemical substance and potential substitutes. Data of this kind will help select materials that behave like the chemical in the applications of interest.

(c) Laboratory tests which have been or are being performed to determine the effect of potential substitutes on humans and other compartments of the environment.

(d) Economic data that would be useful in analyzing the effect that substitution would have on industries involved with the materials and applications of interest.

Presently, responding to data and information needs of these kinds requires searching several computerized information resources. Many organizations conduct thousands of such searches each year. These searches may be labor intensive, time consuming, and can be expensive. Because information resources are administratively autonomous and operate independently from each other, searching for relevant data and information across several facilities can prove difficult. First the lack of an appropriate common catalogue makes it difficult to know which resources should be used. Second, many steps are required to establish connection to and communication with each independent resource and also at times with subsystems of a resources. Third, each resource uses its own query language; thus one request for information will require a different record format and search strategy for each system to be accessed. Fourth, the need for multi-system access causes the user to repeat similar operations for every system searched. Fifth, results of searches often must be screened manually to determine their relevancy. These results still may require categorization and sorting before being used.

Since relevant data and information is often dispersed in and among different resources, the repetition of "common operations" makes the gathering of information awkward, time consuming and is error prone. Timely and comprehensive retrieval is often constrained.

CSIN has progressed through two phases of development. Phase one, or Preprototype in the form of an intelligent terminal was made available to test users in 1980. The intelligent terminal supporting the Preprototype CSIN is a microprocessor-based system. Its features include: (a) automatically connecting to and logging onto a user selected resource; (b) capturing and locally storing data from an information resource; (c) transforming and then transferring data from a user or from material captured from an information resource to the format requirements of another resource, then substituting or introducing this material into the query and transmitting this information to a remote resource; (d) storing search terms used to wholly or partially specify a search in a remote resource; and (e) modifying lists of stored search terms or data which had been received from a remote resource prior to the transformation required by another resource; and (f) being capable of performing these functions in a simulated network environment.

Prototype Version I, (the second phase of CSIN), was delivered to Network Administration in February 1981. Its facilities are presently being tested. Version I of Prototype CSIN is to provide more services and processing capability than exist in the preprototype intelligent terminal. The facilities of the Prototype CSIN are maintained in a stand alone mini-computer capable of supporting users in multi-system transactions through commercial telecommunication networks. Prototype CSIN includes a facility called script. Use of this facility brings into operation a pre-stored computer program or script which mediates between the user and remote systems. The purpose of a script is to automate common sequences of use operations. Use of an information resource is made easier and faster by requiring less knowledge of the processing requirements of the resource, and thus it is possible to reduce the input and supervision required by a user to accomplish a search. Script use involves selection from a user menu of operational features, which include: 1) the selection of options or delimiters for the search; 2) review of the number and kinds of scripts; 3) operation of a script; 4) selection of output options; and 5) selecting the order in which information resources are to be searched.

Presently in development, in a phased approach, is an advanced version of the Prototype. This version to support online, multi-system queries through the use of a uniform language and database schema. It will include more sophisticated scripts and also be capable of supporting users in the development of scripts for their own special requirements. Resources to support users in problems involving chemical identification and the location of data and information will continue to be maintained or become available.

Network Administration plans, through 1982, to use upwards of 50 organizations to test the Prototype CSIN. These organizations will be selected from the private sector, academia, and government agencies (Federal and State). Users will play a role in identifying data and information resources whose utility to many communities would be increased by also being accessible in a network environment.

During even the test period, CSIN users will pay the costs associated with the use of an information resource and share in the costs of operating the management computer. It is the intent of Network Administration to establish, as rapidly as possible, the financial self-sufficiency of CSIN for maintenance, operations and development activities.

Network Administration is negotiating with the owners or managers of various information resources to establish the formal relationships needed to allow them to become accessible through CSIN. These include: the National Library of Medicine (NLM) of the National Institutes of Health (NIH); Chemical Information

System (CIS); Chemicals In Commerce Information System (CICIS--EPA); Lockheed Information Systems' Dialogue; Systems Development Corporation's (SDC) Orbit; Bibliographic Retrieval Services (BRS); and the Chemical Abstracts Registry Service's CAS-On-Line. Network Administration expects to complete its acceptance testing of the Prototype and negotiations with some of the owners of the above resources by the Fall of 1981, and also establish five organizations as test users.

Network Administration believes that blending the concepts of network and intermediary system into a CSIN offers the following array of benefits to its users and developers:

(a) Ease of development. The intermediary concept permits the definition of user interface without affecting the integrity of an information resource. New resources can be added without disrupting interactions with previously interfaced components.

(b) Less duplication of effort. Reducing the need to replicate data generating activities because of an increase in the ability to, when appropriate share data and information.

(c) Uniform search practices. Achieving uniformity through the ability to specify, store and make use of routines for frequently conducted searches whether they are to be accomplished in one or a preselected group of resources.

(d) Quality of search results may be increased. Users are encouraged to perform searches that are comprehensive, timely and complete because of the relative ease and cost-effective manner in which they can be accomplished. Thus a base level of quality for some information products may be obtainable.

(e) Sort feature. The ability to sort retrieved bibliographic information in a manner to reduce the effort required to identify duplicates and collate the final results.

In addition, CSIN should decrease the time and costs associated with searching for relevant data and information. CSIN will favorably impact the manner in which organizations, both in the private and public sectors, plan for, develop, maintain, operate, and cost control their use of data and information resources.

For further information concerning CSIN, please write to:

Dr. Sidney Siegel
Administrator, Chemical Substances Information Network
U.S. Environmental Protection Agency
Office of Toxics Integration (TS-777)
401 M Street, S.W.
Washington, D.C. 20460
U.S.A.
Telephone: (202) 426-9408

References

Bracken, M.; Dorigan, J.; and Overbey, J. "Chemical Substances Information Network," Mitre Corporation Report #MTR-7558, June 1977.

Toxic Substances Control Act. Public Law 94-469.

Wilson, G., et al. "An Analysis of the Requirements for the Chemical Substances Information Network" (2 volumes). Computer Corporation of America Technical Report #CCA-80-07, June 1980.

Mr. **Brown**. Thank you very much, Dr. Siegel. It's certainly a very interesting statement about an important advance in this whole field of information systems.

One of the conflicts that has appeared in the testimony so far in this area is the expression by some of a fear that any large-scale coordinated health information system would, in fact, be centrally directed, centrally managed and, in effect, a coersive expression of Federal Government control. On the other side, of course, there have been numerous witnesses who have stated that systems of a decentralized network nature are technically feasible and do not require a form of centralized control.

Could you comment on that problem from the basis of your own experience with CSIN? Has there been any underlying fear that this was going to produce some repressive central management of the system that would be deleterious to some of the participants?

Dr. **Siegel**. Yes sir, we have encountered such concerns with some of the owners or managers of data and information resources. The initial response of some is to consider CSIN as a threat. The threat comes in part form their not previously having functioned in a technical environment as offered by CSIN. The threat lessens when we are able to describe that CSIN is nothing more than a sophisticated switching mechanism or intermediary system. We further emphasize to resource owners and managers that CSIN does not interfere with their ability to be responsive to the mandate which originally brought their resource into existence. Thus CSIN will cause little or no perturbation in the manner that a data and information resource serves its sponsors. The resource owner or manager very much controls the approach that is taken to most efficiently and effectively serve the needs of the user communities.

All that CSIN administration needs to know is how a resource handles its technical and administrative interface with its user communities. This then allows us to interface an independent and autonomous resource to allow for appropriate use of its data and information. Early in discussions with resource owners we recommend that they review the potential of the CSIN technology for their own management needs.

The technology has now in part and will eventually in its entirety be registered with the National Technical Information Service of the Department of Commerce and thus be available to any private or public sector organization.

Some resource owners or managers respond in ways that lead us to believe that some of their concerns are emotionally based and thus we have become aware that some issues are less technical and more behaviorally oriented.

All we need to do is know what that design is, so that we can interface it for appropriate use and that they themselves might have the ability to use our own switching technology to use as they see fit. There is a behavioral problem, sir.

Mr. **Brown**. That would apply even more so if we moved into a more complex system, such as a complete health information system.

Dr. **Siegel**. I think the number of technical and behavioral problems encountered, would be increased.

Mr. **Brown**. Ms. Schneider?

Ms. **Schneider**. I have no questions at this time. Thank you,

Mr. **Brown**. Mr. Shamansky?

Mr. **Shamansky**. Thank you, Mr. Chairman. I would just like to ask would you elaborate a little bit on the use of the word "behaviorally." Tell me what you mean.

Dr. **Siegel**. It is in part an emotional response. Resource owners or managers tend to be very protective over what they have constructed through very intense and at times competative labors. They become abruptly aware that their resources might now be serving many new communities whose mandates and motives they initially might have little understanding of. In part, some of their response results from the review, analysis, and critique that new groups of organizations could offer to their records.

Mr. **Shamansky**. They're afraid it might appear lacking in some respect or just mere possessiveness?

Dr. **Siegel**. I would think that the latter is the prime concern—the quality.

Mr. **Shamansky**. The behavior you're talking about is possessive?

Dr. **Siegel**. The quality of the data first and then the possessiveness concerning some of these resources.

Mr. **Shamansky**. Thank you, Mr. Chairman.

Mr. **Brown**. Mr. Gregg?

Mr. **Gregg**. No questions.

Mr. **Brown**. Has there been a problem with proprietary data, in which this possessiveness, of course, relates to the fact that the owners obviously wish to recoup their investment and the unrestricted use by owners without some reasonable fee or charge is an infringement upon their proprietary rights, in effect? As the system develops solutions so that the problems—so that in the event that there is a basis for reasonable charges, that the use can be quantified and charged in some fashion?

Dr. **Siegel**. Yes, sir. From the CSIN vantage point, some of these kinds of issues have been identified. The issue of proper compensation has been raised in our ongoing negotiations with resource owners or managers both in the public and private sectors. The commercial resources have a charge rate structure in place so that it will be easy enough to pass this information or set of charges onto the user, through CSIN. Some government sponsored resources will have to establish a charge-rate structure so that the cost of operating for larger sets of diverse communities can be covered. These are all handable issues that we title "billing."

Mr. **Brown**. All right, Dr. Siegel, we'll go on with Colonel McGinnis and General Bickel. If you can remain there, there will be some additional questions.

Colonel McGinnis, we are very happy to have you here. The TRIMIS system has been one, as you know, at least occasionally discussed in the Congress as an example of something or other, and we appreciate the fact that you have come over to tell us more about it.

[The biographical sketch of Colonel McGinnis follows:]

BIOGRAPHICAL DATA

Colonel John W. McGinnis, MSC, USA

13521 Malec Lane
Bowie, Maryland 20715
(301) 262-2248

SUMMARY:

Nov 1976 - Present	Director, Tri-Service Medical Information Systems (TRIMIS) Program Office, a multi-variate Program to improve the efficiency and effectiveness of the Military Medical Health Care Delivery System.
Jun 1975 - Nov 1976	Special Assistant to the Assistant Secretary of Defense (Health Affairs). Responsible for development of special defense medical programs and legislation for CHAMPUS and the reorganization of the TRIMIS Program.
Jul 1974 - Jun 1975	Chief, Program Management Branch, Resource Management Directorate, Office of the Surgeon General, Army. Responsible for advising the Army Surgeon General on matters concerning programming and reprogramming actions for the entire Army Medical Department. Programming actions included manpower, financial, and workload implications.
Jun 1973 - Jul 1974	Comptroller, 8th U. S. Army Surgeon's Office, Korea. Responsible for all manpower, budgetary, and civilian personnel activities for the 19 medical units in Korea. Also acted as the Medical Inspector General for medical personnel in Korea during this period.
Jul 1970 - Jun 1973	Comptroller, Armed Forces Institute of Pathology. Responsible for all budgetary, manpower, and office facilities within the Institute.
Jul 1967 - Jun 1970	Management Officer, 130th Station Hospital, Heidelberg, Germany. Responsible for budgeting, manpower, and facilities planning for the hospital and the Heidelberg Medical Service area, a 180-square-mile area with widely dispersed troops and dependents. Also acted as the Medical Inspector General for the HMSA.

Biographical Data (Continued)

Aug 1964 - Jun 1967	Instructor and Chief. Operations Research and Resource Management Branch of the U. S. Army Medical Field Service School, Ft. Sam Houston, Texas. Taught: Comptroller, data processing, and operations research subjects to 9 different student courses. Also appointed Assistant Professor to Baylor University while instructing in the Baylor/Army Graduate Program of Hospital Administration.
May 1963 - Aug 1964	Graduate School, Syracuse University, Syracuse, New York. Awarded a Masters Degree in Business Administration.
Aug 1962 - May 1963	Student in Advanced Course, Medical Field Service School, Ft. Sam Houston, Texas.
May 1959 - Jul 1962	Management Office, U. S. Army Medical Supply Control Agency, Europe. Responsible for the planning, programming, budgeting of a $50 million annual budget for all medical supplies and equipment within the European Theatre of Operations.
Sep 1957 - May 1959	Registrar, U. S. Army Hospital, Ft. Ord, California. Responsible for all patient affairs and medical records.
Sep 1956 - Sep 1957	Company Commander, Medical Company, 10th Infantry Regiment, 5th Infantry Division, Ft. Ord, California.
Jul 1956 - Aug 1956	Student in the Basic Officer's course, Medical Field Service School, Ft. Sam Houston, Texas.

Colonel McGinnis was born in Erie, Pennsylvania on August 31, 1934. He was graduated from Gannon University in 1957 with a B.S. degree in Business Administration, and from Syracuse University in 1964 with a M.A. degree in Business Administration.

Colonel McGinnis has been an Assistant Professor in Hospital Administration at Baylor University, Waco, Texas; an Associate Professor in Hospital Administration at Trinity University, San Antonio, Texas; and an Associate Professor of Business Administration at St. Mary's University, San Antonio, Texas.

STATEMENT OF COL. JOHN W. McGINNIS, TRI SERVICE MEDICAL INFORMATION SYSTEMS PROGRAM OFFICE, DEPARTMENT OF DEFENSE, ACCOMPANIED BY; COL. RUDOLF G. BICKEL

Colonel McGINNIS. Mr. Chairman and members of the subcommittee, I am pleased to respond to your request that I testify this morning on the TRIMIS program.

The TRIMIS program was established in 1976 to apply standardized automatic data processing techniques to improve the effectiveness and economy of the military health care system.

TRIMIS is the centralized Department of Defense program for coordination of military department requirements, application of existing technology and acquisition of standardized automated medical systems for installation in our medical treatment facilities.

TRIMIS is applying a multiphased management strategy with the goal of providing clinical and administrative automatic data processing support to all of our military medical treatment facilities. To accomplish this goal, the program has centralized the systems acquisition process in a strategy encompassing management phases to satisfy critical near-term requirements, achieve functional and technical standardization, streamline and modernize automated support, accommodate evolving functional and information requirements and exploit advancing information system technology. Phase I is underway implementing a limited number of stand-alone capabilities in selected military medical treatment facilities to meet urgent work center requirements and provide operational experience and further validate medical department requirements. Phase II will facilitate interfacing multiple work center systems within any medical treatment facility. During this phase, standardization of all automated functions and data elements and codes within a medical treatment facility will be achieved. Phase II is scheduled so that provision of these standardized capabilities will begin as the last of the phase I systems are installed. Phase III will provide the definitive base-level system which we refer to as the composite health care system. This system is intended to ultimately provide Department of Defense medical treatment facilities with a minimum level of automated medical record capability integrated with supporting standardized work center systems that are cost justified.

TRIMIS systems are presently providing direct suport to 80 military medical treatment facilities.

The program has implemented a regionalized pharmacy system serving seven Army, Navy, and Air Force medical treatment facilities in South Carolina and Georgia. These medical treatment facilities provide care to approximately 250,000 military health care recipients. The pilot capability was recently installed in the National Naval Medical Center here in Bethesda, Md.

A contract was awarded in January 1981 to acquire three additional pharmacy systems with options for another 12 systems. These systems will support military pharmacies located throughout the continental United States and Hawaii. The first system was installed at the USAF Hospital in Carswell, Tex., in March 1981. The second system is being installed at Walton Army Hospital at Fort Dix, N.J., at the current time, and the third is scheduled for installation at the Naval Regional Medical Center Portsmouth in July 1981.

The TRIMIS formulary production capability operated by the Army's health care system support activity at Fort Sam Houston, Tex., is providing worldwide support to 152 military medical treatment facilities and two Coast Guard hospitals and is scheduled for implementation in the remaining Department of Defense hospitals by the end of fiscal year 1982.

The computer assisted practice of cardiology system is operational in three regions providng support to 58 medical treatment facilities. This system, designed to provide automated electrocardiogram interpretation and reporting, is planned for installation in two more regions in the next few months. These regions will support another 27 medical treatment facilities.

Contracts for the automated cardia catheterization laboratory system and the radiology system were awarded in April 1981. The initial installation of these systems is scheduled to begin in July 1981. Laboratory and patient appointment and scheduling systems are scheduled for award during June and July 1981 with implementation beginning in the early fall.

The registration/admission, disposition and transfer system was installed at the USAF Medical Center Keesler, Keesler Air Force Base, Miss., in January 1981. The system is being used by the program as the basis for developing a core automatic data processing capability for all DOD medical treatment facilities. This core and an associated set of technical standards are the basis for the modularity and standardization necessary to achieve a composite health care system required to support medical treatment facilities that range from small 30-bed hospitals up to a 2,000-bed facility.

Three commercially available hospital information systems are being acquired and will be installed and evaluated as an alternative strategy for the composite health care system as mandated by congressional guidance contained in the fiscal year 1981 Operations and Maintenance Defense Appropriations Act. These systems will be installed in Army, Navy, and Air Force medical treatment facilities.

The automated intrahospital logistics system operating at the Walter Reed Army Medical Center since June 1978 was installed at the National Naval Medical Center in March 1981. This system is being converted from commercial time sharing support to Government-furnished hardware in order to reduce its operational cost and become more cost efficient. The conversion is scheduled for completion in September 1981.

A tri-service dental system is under development by the Department of the Army for the three services. The system is planned to provide support in the areas of management reporting, preventive dentistry, and scheduling of patients. Initially, each military department will have one system for operation and evaluation.

A food service system operating at Walter Reed Army Medical Center since October 1978 is being converted from commercial time sharing to a government owned minicomputer to reduce operation costs.

TRIMIS efforts are also closely coordinated with the Office of the Assistant Secretary of Defense for Health Affairs activities to ensure optimal resource utilization. For example, a test to determine feasible techniques for defense enrollment eligibility reporting/TRIMIS synchronization began in January 1981. This test was conducted at Keesler Air Force Base and coordinated the incoming defense enrollment eligibility reporting system with the registration/admission, disposition, and transfer system. Successful synchronization was accomplished in May 1981. This experience is being used to develop policies for future synchronization of similar TRIMIS data bases with defense enrollment eligibility reporting. It is also planned that the uniform chart of accounts requirement will be satisfied via standard TRIMIS capabilities.

Activities of TRIMIS, the Veterans' Administration and the Public Health Service continue to be pursued through a Subcommittee on Health Care Information Systems of the Federal Health Resources Sharing Committee.

Assessment is a major area of emphasis within the TRIMIS program.

The objective of the TRIMIS assessment process is to provide information relative to costs and benefits on the program's many diverse medical projects. This information assists in setting priorities among projects competing for resources. The TRIMIS assessment process is used to determine the size, importance and value of the program's potential and achieved impacts on the effectiveness and economy of the military health care system. A complete project evaluation set consists of: identification of quantitative and qualitative measures and indicators of effectiveness and economy by a medical review group; a cost-benefit analysis, a preinstallation evaluation; a postinstallation evaluation and a final evaluation report. Followup survey evaluations may be conducted periodically over several years after system installation.

This concludes my prepared statement, Mr. Chairman. I shall be glad to answer any questions you may have regarding the TRIMIS program.

[The prepared statement of Colonel McGinnis follows:]

Statement of

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(Health Affairs)

Before the

Subcommittee on Science, Research and Technology
and the
Subcommittee on Natural Resources, Agriculture Research
and Environment
Committee on Science and Technology
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Tri-Service Medical Information Systems
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Mr. Chairman and Members of the Subcommittee:

I am pleased to respond to your request that I testify this morning on the Tri-Service Medical Information Systems (TRIMIS) Program.

The TRIMIS Program Office was established in 1976 to apply standardized Automatic Data Processing techniques to improve the effectiveness and economy of the Military health care delivery system.

TRIMIS is the centralized Department of Defense Program for coordination of Military Department requirements, application of existing technology and acquisition of standardized automated medical systems for installation in Military medical treatment facilities.

TRIMIS is applying a multi-phased management strategy with the goal of providing clinical and administrative Automatic Data Processing support to all Military medical treatment facilities. To accomplish this goal, the Program has centralized the systems acquisition process in a strategy encompassing management phases to satisfy critical near-term requirements, achieve functional and technical standardization, streamline and modernize automated support, accommodate evolving functional and information requirements and exploit advancing information system technology. Phase I is underway implementing a limited number of stand-alone capabilities in selected Military medical treatment facilities to meet urgent work center requirements and provide operational experience. Phase II will facilitate interfacing multiple work center systems within any medical treatment facility. During this Phase, standardization of all automated functions and data elements and codes within a medical treatment facility will be achieved. Phase II is scheduled so that provision of these standardized capabilities will begin as the last of the Phase I systems are installed. Phase III will provide the definative base-level system (Composite Health Care System). This Phase is intended to ultimately provide Department of Defense medical treatment facilities with a minimum level of automated medical record capability integrated with supporting standardized work center systems that are cost-justified.

TRIMIS systems are presently providing direct support to 80 Military medical treatment facilities.

The Program has implemented a Regionalized Pilot Pharmacy System serving seven Army, Navy and Air Force medical treatment facilities in South Carolina and Georgia. These medical treatment facilities provide care to approximately 250,000 Military health care recipients. The Pilot capability was recently installed in the National Naval Medical Center to support the new facility.

A contract was awarded in January 1981 to acquire three Pharmacy Systems with options for another 12 systems. These systems will support Military pharmacies located throughout the Continental United States and Hawaii. The first system was installed at the USAF Hospital Carswell in March 1981. The second system is being installed at Walson Army Hospital. System number three is scheduled for installation at the Naval Regional Medical Center Portsmouth in July 1981.

The TRIMIS Formulary production capability operating at the Army's Health Care System Support Activity, Ft. Sam Houston, Texas, is providing worldwide support to 152 Military and two Coast Cuard hospitals and is scheduled for implementation in the remaining Department of Defense hospitals by the end of Fiscal Year 1982.

The Computer Assisted Practice of Cardiology System is operational in three regions providing support to 58 medical treatment facilities. This System, designed to provide automated electrocardiogram interpretation and reporting, is planned for installation in two more regions during the next 12 months. These regions will support another 27 medical treatment facilities.

Contracts for the Automated Cardiac Catheterization Laboratory System and the Radiology System were awarded in April 1981. The initial installation of these systems is scheduled to begin in July 1981. Laboratory and Patient Appointment and Scheduling Systems are scheduled for award during June and July 1981 with implementation beginning in the fall of 1981.

The Registration/Admission, Disposition and Transfer System was installed at the USAF Medical Center Keesler, Keesler Air Force Base, Mississippi, in January 1981. The system is being used by the Program as the basis for developing a "core" Automatic Data Processing capability for medical treatment facilities. This "core" and an associated set of technical standards are the basis for the modularity and standardization necessary to achieve the Composite Health Care System required to support small to large facilities.

Three commercially available Hospital Information Systems are being acquired and will be installed and evaluated as an alternative strategy for the Composite Health Care System as mandated by Congressional Cuidance contained in the Fiscal Year 1981 Operations and Maintenance Defense Appropriations Act. These systems will be installed in an Army, Navy, and Air Force medical treatment facility.

The automated intra-hospital logistics system operating at the Walter Reed Army Medical Center since June 1978 was installed at the National Naval Medical Center in March 1981. This system is being converted from commercial time sharing support to Government furnished hardware in order to reduce its operational cost. The conversion is scheduled for completion in September 1981.

The Tri-Service Dental System is under development by the Department of the Army. The system is planned to provide support in the areas of management reporting, preventive dentistry and scheduling. Initially, each Military Department will have one system for operation and evaluation.

The Food Service System operating at Walter Reed Army Medical Center since October 1978 is being converted from commercial time sharing to a Government owned minicomputer to reduce operational costs.

TRIMIS efforts are closely coordinated with other Office of the Assistant Secretary of Defense (Health Affairs) activities to ensure optimal resource utilization. For example, a test to determine feasible techniques for Defense Enrollment Eligibility Reporting/TRIMIS synchronization began in January 1981. This test was conducted at Keesler Air Force Base and coordinated the incoming Defense Enrollment Eligibility Reporting System with the Registration/Admission, Disposition and Transfer System. Successful synchronization was accomplished in May 1981. This experience is being used to develop policies for future synchronization of similar TRIMIS data bases with Defense Enrollment Eligibility Reporting. It is also planned that the Uniform Chart of Accounts requirement will be satisfied via standard TRIMIS systems.

Activities of TRIMIS, the Veterans Administration and the Public Health Service continue to be pursued through a Subcommittee on Health Care Information Systems of the Federal Health Resources Sharing Committee.

Assessment is a major area of emphasis within the TRIMIS Program.

The objective of the TRIMIS Assessment Process is to provide information relative to costs and benefits on the Program's many diverse medical projects. This information assists in setting priorities among projects competing for resources. The TRIMIS Assessment Process is used to determine the size, importance and value of the Program's potential and achieved impacts on the effectiveness and economy of the Military Health Care System. A complete project evaluation set consists of: Identification of quantitative and qualitative measures and indicators of effectiveness and economy by a Medical Review Group; a cost-benefit analysis, pre-installation evaluation (Period X), post-installation (Period Y) evaluation and a final evaluation report. Follow-up survey evaluations (Period Z) may be conducted periodically over several years after system installation.

This concludes my prepared statement, Mr. Chairman. I shall be glad to answer any questions you may have regarding the TRIMIS Program.

Mr. Brown. Thank you, Colonel.

Colonel Bickel, would you have any additional statement you would like to make?

Colonel Bickel. No, sir.

Mr. Brown. Colonel McGinnis, can you give us at this stage, which isn't necessarily the best stage, any succinct evaluation of the cost-benefit aspects of the work that has been done so far? Are you able to, either on the basis of evaluations that you have made, or on the basis of educated guesses, give any indication of what the situation is? Earlier witnesses have testified that there is a quantity of data in this field with regard to good cost benefit analyses of automated of all kinds of hospitals, that there is a great need for it. I'm sure that part of the snipping that comes from Congress, either DOD or myself, is based on their desire to have these hard figures, you know, that show we are saving the taxpayer dollars. And I'm sure that you are prepared to respond through your evaluation system to that kind of approach. I just wondered if you can give us a hint now as to what it looks like?

Colonel McGinnis. If I might, let me give you an example. In 1977 OMB wanted us to prepare a prospective seed cost benefit analyses on all of our systems we were going to undertake. One was the pharmacy system and, if I might, I could extrapolate what we found from that.

In 1977, prospectively speaking in those terms, in 1977 dollars, a system would be cost beneficial in our medical treatment facility of 200 beds, which the most applicable in costs to the Department of Defense. It could have been cost beneficial at 19.6 cents per prescription. We installed this pilot system in 1978 and brought it up and started running. In 1979 we completed our first evaluation of it, and we updated our cost benefit analyses every year since then, and currently the cost benefit study shows it would be cost beneficial at 26.3 cents per prescription.

Validated cost is 12—between 11.8 and 12 cents per prescription, right now, running in our eight pharmacies where we have it running. So it's extremely cost beneficial.

Mr. Brown. All right. Now, what about some more difficult areas, such as the automated cardiology analysis, that kind of thing. Is there technology that will allow you to do an objective cost benefit analysis, because of the fact that you are involved in the measurement of certain intangibles such as improvement of diagnostic procedures? What can you say about this kind of problem?

Colonel McGinnis. Let me turn that over to Colonel Bickel. That's his area of specialty.

Colonel Bickel. What I might say in answer to that I think certainly as you indicated depends on what you're going to consider as benefits and how you evaluate the benefits.

Mr. Brown. Well, that's the problem you have to solve.

Colonel Bickel. Yes, sir. What we did, as Colonel McGinnis mentioned, the CAPOC system is a network system for electrocardiogram analysis that we had begun to install and he had tested the system in the first region in which it was installed. What we did to determine benefit there is to look at three categories of patients who, on the one hand, may require an immediate response, where there is an emergency or there is a need for a response. Second, a priority response and third, electrocardiogram done on a routine basis that does require that urgency of response, in terms of acceptable times for what a physician would want to properly treat a patient. And, having done that, we then looked at the current system as it then existed prior to installation of the automated system and looked then further at the system after it was installed to attempt to quantify that intangible area of benefits.

It's much more difficult to quantify the benefit of having a validly interpretated electrocardiogram at a remote site where a cardiologist does not exist and the patient is there, who has a question of a condition that could be serious. And that is I think a part of the problem that runs throughout medicine—to determine in essence the type of benefit of the care being provided and the worth of treating patients and doing the job that medicine is there to do. I don't know exactly how to answer the question either, and I think it's one that many people have wrestled with.

Mr. BROWN. Is the question any different in its essence from trying to determine the cost benefit of installing the CAT scanner, which is a very popular and expensive kind of technology today?

Colonel BICKEL. I think it has many of the same kinds of aspects. You weigh the cost against the kinds of benefits that are asserted and some of which are clear in terms of increased diagnostic ability that such devices have. The intangibles will still be with us, and I think there is an element of subjective judgment in any case in such a thing as where the benefits lie of improved diagnosis and of lifesaving.

Mr. BROWN. There's no question but what the CAT scanner gives you an improved diagnostic capability, but how do you quantify it. It's the same problem as with the cardiac system.

Colonel BICKEL. What we have done in our strategy for analyzing systems is we realize some things are never going to be quantified in ways that people can agree with. We do want to, however, set forth those things we can measure in terms of how well systems perform or how well the pharmacy or the laboratory or the medical record functions perform as compared with things we can measure about them prior to installing such a system.

Now, it's agreed that that only gives a partial measure of the worth of such a system. If we can get cost benefit in those terms, as Colonel McGinnis mentions with the pharmacy system, the cost per perscription having come way down, we feel we can talk to people who are managers, who would otherwise have to divert their resources to other types of things, who would have that option in terms of benefit or lack of benefit of making this kind of a decision. The additional sorts of things—picking up potential allergic reactions that did not occur, picking up inadvertent therapeutic misadventures that might well have occurred. We have documented instances in which the system has put up the flag and has doubtless prevented inpatient problems or even deaths by this kind of activity. That is something that is very difficult to quantify.

So what we have gone after at least is to establish benefits in ways in which we can measure them in before and after studies and then simply asserting the other benefits to the best extent we can without further quantification of cost and benefit.

Mr. BROWN. When you do an analysis of an EKG—electrocardiogram—ECG, I think, or EKG——

Colonel BICKEL. They're equivalent.

Mr. BROWN. Whatever—by automated system and it shows anomolies, you still have to have further analysis by visual observation.

Colonel BICKEL. Yes, sir. The system is excellent at detecting normal cardiograms. The cardiologist will universally, in almost all cases, accept a computer reading of normal. In the case of certain things, certain kinds of arrythmias, certain other borderline situations or cases in which clinical correlation with other facts that the computer analysis program does not have—when these things are needed, then the cardiologist has to be there to review abnormals.

Mr. BROWN. Mr. Gregg?

Mr. GREGG. Thank you, Mr. Chairman. As you move into this phase III, what are you going to have in the definitive case level systems?

Colonel McGINNIS. We anticipate a core that would be exportable to any of our medical treatment facilities regardless of size, and the core would consist of all patient administration functions. And that is what we have operating at Kessler now except for a couple of minor parts. That's registration, admission, disposition, transfer and business office function, and the clinical record cover sheets. And because they share so much of the same demographic data between the two systems, we are anticipating that possibly a patient appointment and scheduling system could also be satellited right over the top of the patient administration system, and we are investigating that at the current time.

We think we can install those in a very cost effective manner even in the smaller hospitals. As we go further, then, it will only be into the systems that the hospitals can cost justify, and there's no doubt in anybody's mind that a 200- or 250-bed hospital can justify an automated laboratory system of some sort. But a 50-bed small hospital is going to have a hard time cost justifying an automated lab. It looks like we'll be able to interface an automated pharmacy rather far down in the system, but it can only be based on what each hospital can cost justify to be interconnected with that core.

Mr. GREGG. You're going to have the core available.

Colonel McGINNIS. Yes.

Mr. GREGG. To anybody who can justify it from a cost standpoint?

Colonel McGINNIS. Yes. And we think we're going to engineer it at a low enough cost that it will be available to almost every hospital.

Mr. GREGG. And what else would be core size? Anything else?

Colonel McGINNIS. That's all.

Mr. GREGG. Cardiology?

Colonel McGINNIS. There are things interconnected with the core that will be cost justified based upon each hospital, requirements but with the core itself, that's all that would be there.

Mr. GREGG. Do you have an educational arm?

Colonel McGINNIS. No.

Colonel BICKEL. Let me address that briefly.

Mr. **Brown**. Excuse me. Can I ask you to clarify for me what you mean by educational? Are you referring to inservice training of the professionals or some other form of education?

Mr. **Gregg**. Inservice training of professionals.

Colonel **Bickel**. In the case of service systems that are used by professionals within the hospital, yes, there is a training stage that has to go along with each individual system. For example, as we put in the electrocardiogram analysis system, the cardiologists were trained to use it, were trained to interact with the system in entering additional comments about the abnormal electrocardiograms and the like. And this is ongoing owing to the natural turnover of personnel within hospitals. That's really an ongoing activity. Even once you have done it for the facility, one needs to continue to do it. So any system that is being used, the users have an ongoing educational need.

The issue of computer system instruction, which I thought you were pointing to, is one we have not gotten into specifically as regards, for example, continuing medical education and the like, except to do a small exploratory study of a couple of commercially existing systems. But the ongoing education that will be required as systems expand, particularly as the medical record gets in in later stages of the system will, I think, be a substantial part of what will have to be done a continuing basis to make the system viable.

Mr. **Gregg**. Are you thinking of going into the continuing education area?

Colonel **Bickel**. The pilot study we did showed really rather inconclusive results. It is unclear that this method right now, given current state of the art technology—to be commercially available timesharing services and one system that exists on a stand alone computer—it's really unclear that these are more beneficial and better accepted than other modes which include journals, which include video presentations, and which include other means and modalities of presenting information.

I think that this state of the art, though, is beginning to evolve and we will of course continue to watch it.

Mr. **Gregg**. When you get to the phase III structure, do you have a time frame?

Colonel **McGinnis**. We are aiming for the fall of 1984 or the spring of 1985.

Mr. **Gregg**. At that point will your systems have any private applicability? Will they be suitable in a private sector atmosphere?

Colonel **McGinnis**. We believe they will. We believe the standards which we are developing will allow commercially available systems to interact with our core, will be made available to the public at large and will help solve the problem of incompatibility of systems and will be in the public domain. Also, the steps we have taken toward standardization of data elements and codes is a step that other people could learn from. We had to learn it. It was the way we had to learn to walk and it was the period of time when the program was accused of going rather slow. Our slowness was giving all the military departments an opportunity to interpret these data elements the same way and it took a long time.

Mr. GREGG. Is there any proposal or are you considering going public with your procedures once you get into a position where you feel it's working correctly?

Colonel McGINNIS. They are public at the current time for anybody who wants access to them, and we make them available to anyone. We are planning this summer to put everything we have documented so far on the NTIS service and make it available through NTIS.

Mr. GREGG. Thank you, Mr. Chairman. I have nothing further.

Mr. BROWN. Thank you, Mr. Gregg.

As you probably know, Colonel McGinnis, a number of the previous witnesses have brought up some of the obstacles to the development of these integrated systems, some of which you have referred to—the standardization problem—always a very difficult problem. I would just like for you to comment again as to the feasibility of resolving this problem if you focus on it sufficiently. I have heard recently and seen in the literature that the Defense Department is moving toward a standardized computer language for example, or a preferred computer language—I'm not sure which—but that this is intended to replace dozens or hundreds of computer languages. The problem is both—well, it's curious in even level. It's an international problem for example. I'd like to have you offer a few comments as to the need to approach this problem on a broad basis and the feasbility of achieving success if you direct adequate effort at it. In other words, how tough has it been to get as far as you have gotten in this operation?

Colonel McGINNIS. It has been very difficult trying to comply with all of the guidance that has been provided to us. [Laughter.]

Mr. BROWN. By that I assume you refer to Congress.

Colonel McGINNIS. It's the same from many sources. We feel it is a requirement laid upon us to be hardware independent and software independent. I don't know if those terms bother you when I use them. I don't like to use them. I'm not a technician, but to achieve that requirement has been the hardest problem that we have come up against, and it requires standardizing on some higher level language, and at the present time we are using COBOL. We will go over to ADA when Defense adopts ADA as its formal language. But we had to standardize on something, and then we had to develop software modularly so it could be moved from one piece of hardware to another—the same software package.

We are experimenting with how well we have done that right now, and the test kicks off next Monday morning, hard and fast. We have taken the registration system, which is one piece of hardware at Kessler Air Force Base, and operating very, very well, and we are going to put it on another piece of hardware, and we think we can do it in about 100 to 150 days. If we have designed it as well as we think we have and engineered it as well as we think we have, we will do it and we will have it running about September-October time frame, and I'd be glad to come back to the Congress and tell you how successful we were.

I'm almost dead sure we're going to pull it off, and if we can do it with that set of hardware, we can go anywhere. So it's been a tough problem getting there, but I think we have finally climbed that mountain.

Mr. Brown. Is this not a situation where the problem is not only the technical problem of agreeing on what is, say, an optimum standard but then the additional human problem of reeducating or remotivating the owner, reconvincing a large number of users of alternate kinds of standards that they have to go through a relearning process to adapt to the new standards?

Colonel McGinnis. Yes. If we have done it as well as we think we have, to the user, the end item will be transparent. He will never know the difference. We have done it with the pharmacy and the users at all medical treatment facilities don't know where the computer support is coming from, but they can go from the Navy facility in Charleston to the Army facility at Eisenhower or over to the Air Force facility at Charleston Air Force Base, and the system is identical. We are using it to cross-train the service personnel in those areas and cross-supporting each other.

So we have obviously done a pretty good job with the pharmacy and the transparency issue. We think we are going to have the same kind of success with the registration, admission, disposition, and transfer system. The user will only see the screen, and the screen will be the same everywhere, so we won't have to contend with the problem that you just referred to.

Mr. Brown. Let me ask you a question which I'm sure you get from many congressional committees, and that is to estimate the cost to date and cost for the ultimate system, just to give us an idea. And I know you can't do this accurately, probably, but give us a sense of the magnitude of what we're talking about.

Colonel McGinnis. For the composite health care system or what we've spent to date or——

Mr. Brown. Well, I'm sure that you have sold this on the basis of ultimately the composite system, or it's been forced on you, whatever the case may be.

Colonel McGinnis. Yes, sir.

Mr. Brown. And on the basis of expectations that the magic power of computers was going to produce great wonders. I'm interested in what your actual cost to date has been, what you project in 1985 or whenever you have the composite system, and what the ultimate cost is likely to be.

Colonel McGinnis. Sir, our costs to date, since 1976, are about $111 million. Not all of it has gone to the composite health care system. It's been used to pay salaries, and to support systems all ready up and running. We have been limited by some guidance from Defense that we would not spend in any one fiscal year more than 20 percent on this developmental effort, the composite system, and we have been staying well under that. So far we have been averaging about 17 percent a year on that developmental effort, and that's only been going on in the last 2 years.

Mr. Brown. All right. Do you have a run-out cost?

Colonel McGinnis. Probably in the neighborhood of about $370 to $380 million.

Mr. Brown. Do you have a line item appropriation on this system?

Colonel McGINNIS. It has been combined with other health affairs systems and medical information systems budget line items now. It's the predominant figure in that line item, yes. For fiscal year 1982, it's projected at $46.9 million, of which TRIMIS will be $31 million, and the other defense agency—health affairs agency—will be the difference.

Mr. BROWN. Well, that's exactly what I wanted to have on the record. I recall in the earlier reports that I saw, we started talking about a $200-million figure, and I presume that was the original estimate of what it would cost for developing the complete system.

Colonel McGINNIS. Yes, sir. We hope, if we have engineered it well, we can put it in our basic core medical treatment facilities at somewhere around a $150,000 figure, and it would be very cost beneficial around that figure. That's prospectively speaking; we haven't tried it yet, so I can't give you any update on that.

Mr. BROWN. Just to clarify for me what you mean in your statement, you referred to the synchronization of TRIMIS data bases with defense enrollment eligibility reporting system. Just what do we mean by that statement?

Colonel McGINNIS. Are you familiar with the DEERS program, Mr. Chairman?

Mr. BROWN. No.

Colonel McGINNIS. Congress mandated to health affairs that we find out exactly who we are responsible for treating, and the outcome of that study was a defense eligibility and enrollment system which TRIMIS prototyped in 1978-79 for OSD (health affairs), and it publicly went on a competitive basis, and a contract was awarded to implement DEERS worldwide to find out exactly how many beneficiaries and active duty we are responsible for treating. The number, depending on who you talk to, was from 7.5 million to 12 million.

So the defense eligibility enrollment system is well underway. In fact, I was at the conference on it just yesterday in Colorado Springs. It is enrolling individuals, and we'll have all the people in any area—in a data base by area, but it will also be a centralized data base at the Defense Manpower Data Center.

TRIMIS, when it installs a system, has to have an initial load of patient demographic data. We will get that initial load of demographic data from the DEERS data base. That's the first part of the synchronization. And later as the patients present for care, we will check their eligibility status through the TRIMIS terminals. And we have that operating right now at Keesler AFB, tied to Alexandria, Va., to the DEERS data base. The interaction takes place in about 2½ seconds from the time the patient provides the prescription to the window at Keesler until we find out whether they're eligible or not.

Currently at Keesler we're checking all inpatient admissions and about 15 to 20 percent of all outpatient visits.

Mr. BROWN. Well, now that I know what it is, I assure you it's going to be very popular with Congress. We need access to that kind of information.

Colonel McGINNIS. Congress mandated that a complete enrollment system be finished, and in order to expedite it, it has given us additional funds to complete it, and it will be done by the end of next year, 1982 in conus, so it looks like it's right on track.

Mr. BROWN. As you probably know, one of the normal aspects of the congressional caseload has to do with service veterans' contentions that they have service-connected disabilities or some other problem due to military service, frequently requiring an effort to ascertain previous health history records, and we sometimes have a great deal of difficulty doing that. I have had several such cases, as a matter of fact.

May I assume that the full development of this system will lead to some easing of that problem of accessing health records with service personnel 20 years after they get out of the service?

Colonel MCGINNIS. It is not one of the requirements that we have been asked to address, but yes, it would be reasonable to expect our system to do that. But we are talking about when we reach what we refer to as the phase IV system, which is the total integration of all the medical facilities and the spinning off of data up to the Department of Defense in a consolidated form. Then it would be available, I do believe.

Mr. BROWN. Dr. Siegel, does your system have a requirement for language standardization?

Dr. SIEGEL. No, sir. Since CSIN is basically an intermediary or switching system with the capability of doing sophisticated pattern matching, it has no requirements for standard computer languages or record and data formats in any resource that we can presently interface or any we would consider interfacing. What you find in the arena of science, whether it is the discipline called computer science or any other scientific discipline, there are many languages or modes of communication. The ones that are good will survive and be useful for a long period of time. The ones that are inefficient will die off. These decisions are properly the responsibility of the resource owners.

Mr. BROWN. Do you have any rough dollar figures with regard to the cost, both to date and projected for your system?

Dr. SIEGEL. Yes, sir. From the time of development of the concept which took place in late 1976 and activities which include our ongoing contract efforts, some of which go through fiscal year 1982, a total of $4.46 million will have gone into concept, requirements analysis, design, implementation, and the use of consultants. In other activities which are auxiliary to the ones mentioned a total of $0.46 million has been committed.

We are aware that more development work will be needed for CSIN, possibly at the level of $0.50–$1 million a year past fiscal year 1982. Presently, there is enough technical framework in place so that in discussing the capabilities of existing CSIN facilities with interested organizations we can determine for them the cost of including new, modifying existing and making accessible data and information resources of interest by interfacing CSIN to them.

Mr. BROWN. Thank you.

Mr. Scheuer, do you have any questions?

Mr. SCHEUER. Yes. I'd like to ask both Dr. Siegel and Dr. McGinnis, what do you consider to be the payoff for the investment? I'm not asking you for a sophisticated cost/benefit analysis. In general, what do you consider the benefits we would enjoy? What are the savings, and what are the improvements in patient diagnosis? What has the taxpayer gotten for his dough? What has your system gotten for its $4.4 million investment?

Dr. SIEGEL. Sir, some of the payoff which I'll describe is payoff for the future and some is relevant to immediate problems of increasing the efficiency and effectiveness of a program in handling its data and information problems. Once data and information resources relevant to a problem or set of problems can be identified, a technology such as the one supporting CSIN can be used to allow an appropriate sharing of the contents of those resources. Thus there will be an increase in the opportunity to reduce duplicative efforts and effect savings in this manner. The other mode of payoff of a CSIN is to increase productivity of an organization's staff in handling their problems associated with data and information. Network administration has done some productivity experiments which are best described as preliminary and not rigorous in design.

Mr. SCHEUER. Which are not what?

Dr. SIEGEL. Not rigorous. They are not scientifically well designed, yet they make us look good for the increase in productivity.

Mr. SCHEUER. I'd say they were very well scientifically designed.

Dr. SIEGEL. We don't want our experiments to be self-fulfilling prophecies, so when we do go into scientifically well-designed productivity experiments, that design will be reviewed by outsiders to make sure we are not self-fulfilling our own prophecies.

Mr. SCHEUER. But your preliminary scrutiny indicates what in terms of benefits?

Dr. SIEGEL. Our preliminary survey indicates that benefits resulting from more efficient and effective use of staff at all levels in an organization will accrue through the use of CSIN. The qualitative and quantitative aspects of those benefits will increase in number and kind as CSIN becomes more sophisticated as an intermediary system.

Mr. SCHEUER. Can you in any rough, crude way relate costs to benefits?

Dr. SIEGEL. I think in relating costs to benefits I would run into some of the same kinds of problems my colleagues from the armed forces have run up against. The costs of using an information resource through CSIN will be higher than if it were used without CSIN. If, as I have previously remarked, rigorously designed productivity studies continue to support the apparent increase in productivity and staff effectiveness, then these most likely would be costs which are acceptable to an organization's management. Further, if an organization realizes that it does not have to duplicate some information activities but could share data through CSIN—this is a benefit accrued by not having to unnecessarily invest funds. Identifying and quantifying the potential benefits of CSIN can be done, but it is a set of nontrivial tasks which is complexed by the fact that CSIN is to service all the communities—government—Federal and State—industry and academe.

Mr. SCHEUER. Thank you.

Colonel McGinnis?

Colonel MCGINNIS. First off, I believe it will benefit the taxpayer in that we have inhibited all tri-service duplicative developments from taking place. Nothing can begin without sanction from the TRIMIS program. All three services were developing laboratory systems, pharmacy systems, radiology systems. Now there is only one program for buy or build.

Second in the cost/benefit or cost/effective area, I believe we are seeing pharmacies run more efficiently. I can document the fact on one pharmacy where we ran a test and it ran 2 years consecutively with 14-percent less dollars expended on drug inventory, without taking into consideration inflationary factors. So there would have been even more of a saving.

Mr. SCHEUER. How would that 14 percent as a dollar savings relate to the pro-rata share of the investment and the annual cost of maintaining the system that you would apply to that one pharmacy, in some rough, crude way?

Colonel McGINNIS. You're talking about a numerical estimate of cost?

Mr. SCHEUER. Yes.

Colonel McGINNIS. We do formalize cost/benefit savings, and that would be taken into consideration when we do our analysis.

Mr. SCHEUER. Have you done a cost/benefit analysis?

Colonel McGINNIS. Yes, we have.

Mr. SCHEUER. How did it come out?

Colonel McGINNIS. Oh, I mentioned it earlier. We predicted in 1977 that our pharmacy system would be cost-beneficial at 19.6 cents a prescription. We have updated that every year since then, and it's now up to 26 cents a prescription. The system that we have just completed a test on, down in the Charleston, S.C., region is running at 12 cents a prescription, so it's obviously quite cost beneficial.

Mr. SCHEUER. Thank you very much.

Mr. BROWN. Thank you all very much, gentlemen. We haven't exhausted all the questions we would like to ask, but that's going to be impossible. If we may continue to have your cooperation in responding to written questions, we would very much appreciate that.

Mr. BROWN. Our next witness this morning is Dr. Karen Duncan, Consultant, Hospital Information Systems.

STATEMENT OF DR. KAREN DUNCAN, CONSULTANT, COORDINATED HEALTH INFORMATION SYSTEM

Mr. BROWN. Dr. Duncan, we are very pleased to have you here this morning and would look forward to your testimony on this important subject matter.

Dr. Duncan, the full text of your statement will be placed in the record. And if you desire to summarize it, bridge it, or focus on particular points, you may.

Dr. DUNCAN. Thank you very much, Mr. Brown. I appreciate the opportunity to talk to you today.

The subject of a Comprehensive Health Information System is a very exciting and interesting one, and in my full testimony, I started by discussing need-benefit and issues. But I won't say anything about that today—because this is the day for planning—other than to stress that I believe, as do the other witnesses, that the needs and the benefits and the issues are the critical areas we address when we go into the planning process.

One of the first things we should think about in planning is, just what is this Comprehensive Health Information System that we want to plan toward? A CHIS does have physical aspects, but when you focus on the physical details of a concept this complex and intricate, you will find that you're developing a detail-driven system, rather than a plan-driven system.

So, I prefer to think of a Comprehensive Health Information System as a concept, as something that will provide a policy framework for information flow in the health care delivery system. It must be an integral and vital part of the health care delivery system. It has to be or it won't work.

The CHIS will provide a set of facilitating mechanisms to allow better information flow to and from and throughout the health care system. I think of the CHIS as a model in which we have, on the one hand, a set of ever-evolving needs that drive the system. On the other hand, we have diverse sources of information that also will be continually changing, to provide input into the system. In between, we have a very complex mechanism for acquiring, evaluating, aggregating, maintaining, updating, retrieving, formatting, brokering, and delivering information. So a CHIS is quite complex.

There will be many feedback loops, and there must be a strong infrastructure and lots of rules. But most of all, the system and the framework must be flexible, because as we solve the current problems in the health care delivery system, new ones are going to come up, and we must be able to meet these new challenges.

With that in mind as our goal for the Comprehensive Health Information System, my first thought is, where in the world are the people with the talent to plan this sort of system? You cannot leave the planning and development of such a system to chance. You need multi-dimensional people—with multi-dimensional vision, people who understand and are skilled in systems theory, who understand the technology; people who understand the health care delivery system.

These kinds of people are very rare, and I am concerned about that. But I am convinced that these are the kinds of planners that are needed—people that are not mired in some vested interest or aspect of the system—although certainly they too, have a contribution to make.

The first thing these planners must do is to develop a thorough understanding of the problem. In the traditional systems approach, the first thing one does to develop understanding is to assess the needs and benefits. But since we're talking about a concept, I think that the first thing you need to do is look very carefully at the concept itself, in the very large sense.

Are we talking about a statistical system? Are we talking about, as Dr. Gabrieli did in his testimony, a medical system that's going to provide surveillance of treatment records and immediate feedback to physicians? Are we talking about all of these things? What is really involved? Then we must try to put some sort of value on these different things. What good is going to come of them?

The second major area is a consideration of the issues. We have raised a lot of issues and I notice a lot of the same ones keep coming up about physician resistance and privacy. But I think these only scratch the surface of the issues. There are strong administrative and social and ethical issues, but the professional arena is going to be where the biggest ones lie, because the very idea that you're going to impose a system that will be dependent on 8 or 9 million health care professionals on those professionals is out of the question. These people have got to be won over; they have got to be brought into the planning process.

The third thing needed is, again, the lessons of the past. There is a lot of work being done that we can learn from, and not just work in statistics and data bases. For example, the National Library of Medicine has a lot of experience in medical data bases and information delivery mechanism. They are people who have had experience in how to cost out things like this. Who is going to pay for this service?

The fourth area, by way of providing background for the planners, is reviewing the status of the technology.

Mr. SCHEUER. Dr. Duncan, can I ask you a question? I don't want to interrupt the flow of your testimony, but when you say "planners," do you mean national planners at the Federal level, designing a system for the country? Or do you mean regional planners? Or do you mean planners for an individual hospital? At what level do you perceive the planning to possibly take place?

Dr. DUNCAN. I definitely do mean at the national level, and at the very conceptual planning stage. I'm talking about national planners who will come from all areas and who will be top people that we can bring together to bear on this problem.

Mr. SCHEUER. You are designing some kind of a national network I take it?

Dr. DUNCAN. Framework.

Mr. SCHEUER. Framework. Excuse me.

I didn't mean to interrupt you, but you have used the word "planners" a couple of times, and I was curious as to at what level these planners would be doing their job?

Dr. DUNCAN. Certainly, that as one gets deeper and deeper into this, you would involve planners at all levels. But initially the global look I think is first, the top-down planning approach.

Mr. SCHEUER. Right.

Dr. DUNCAN. Now, in terms of technology, I have to differ from most of the witnesses that you have heard, in terms of available technology. It is quite true that we have technology available today for health computing that is not being used. Technology is way ahead of our application of it.

However, I must caution the committee. The technology does not exist in its entirety for this comprehensive coordinated health information system. So, one of the things that the planners are going to have to understand is what is going to be needed. Then we must call for its development in the commercial sector so it will be available when we need it.

And as an example of this, Dr. Gabrieli mentioned putting 500,000 new terminals in 500,000 doctors offices. Our telephone system would go under on the first day. And there is a lot of technology——

Mr. SCHEUER. Are you sure of that?

Dr. DUNCAN. Yes. If all the terminals were used as Dr. Gabrieli envisioned.

Mr. SCHEUER. I am on the Telecommunications Committee. I have just come on it since January, so that's a whole new world that's opened up to me. But I am absolutely astonished what you can push through a wire—thousands and thousands of simultaneous messages.

Dr. DUNCAN. Well, certainly——

Mr. SCHEUER. If you have been told by experts that the current system couldn't handle this new load, I would accept that.

Dr. DUNCAN. I would simply point to the fact we are evolving lots of new telecommunications systems that are going into place and that are going to use satellite communications and so forth. This is real testimony to the fact that the current system is not going to handle the information loads of the future. In fact, it didn't even occur to me that was a controversial point. In particular, not so much long lines, but local delivery of service, a lot of local telephone systems cannot cope with this.

Now, of course, if you put 500,000 terminals into doctors' offices today, it wouldn't affect the telecommunications system, because nobody would use them. So that's not an issue today.

What we're talking about is, if you really have the continuous surveillance of medical problems and treatment and live interaction within the full-blown system that we have heard about—the pie-in-the-sky system we have heard about the last few days—this is where the problems would come in, I think, but that is really not appropriate for me to say. This is one of things I think we shouldn't do at this point—draw conclusions about the shape of the final CHIS. The planners should look at that sort of thing and tell us our options.

Another thing is the human-machine interface. I think it is foolish to think we are going to standardize on today's computer terminal keyboard, which is our popular technology, as being the way the medical system is going to interface with the comprehensive health information system. We need a great deal of research in human interface hardware and software, more human engineered systems.

Another inadequate technological area is data base technology. The current hospital information systems, for example, have tremendous potential for good in the individual hospitals. But the fact of the matter is if you try to use the existing hospital information systems for the surveillance or to connect with automated consulting and computer-aided diagnosis and decisionmaking, by and large, they would be quite swamped. They need redesign.

The problem is that these hospital information system vendors have 15 years invested in these systems and, indeed, the systems were based on technology and concepts that are 15 years old, too. They've got to start getting their money out of these before they can begin to invest in systems of the future. They also need guidance from the CHIS planners as to what sort of systems to design for the future.

So, there is a lot of work to be done in the technology area.

Mr. **Brown**. Dr. Duncan, may I ask you to suspend for a few minutes? We have to vote on an amendment to a bill on the floor. It will take about 10 minutes to sort of go over and do that, if you don't mind.

I was hoping we might be able to finish your presentation, but I think that would be unfair to you. So we will recess the subcommittee for 10 minutes and finish your statement when we return.

[Recess.]

Mr. **Brown**. The subcommittee will come to order.

In the interest of time, I'd like to proceed with your testimony, Dr. Duncan. And I apologize, again, for the interruption. And you may proceed.

Dr. **Duncan**. Thank you.

When we stopped, I had just completed a list of four preliminary steps or background investigations that the planners should make. They should assess and prioritize the needs, investigate sociological, political, and professional barriers and issues, review the status of technology and develop likely future options, and finally study progress and results of current projects that are related to CHIS concepts.

This is the point at which the planning committee should begin to develop their conceptual models for how a CHIS might look, including where it should be, who should develop it, how are we going to pay for it—a lot of issues that should begin to be resolved as we address them and try to overcome them. Some other questions are what are we going to do about quality of data? How are we going to find personnel? What is the educational process that we're going to have to go through in all areas—consumers and providers alike—in order to achieve such a system?

I know it's a big order, but I think that one can eventually get a handle on it.

The next step I'm recommending is the design of such studies as cost-benefit and demonstration projects that will be needed to resolve various issues and problems that we have not been able to find out through the study of the existing systems. Then, at the same time, there are some concurrent prototype activities that can be going on at every point, one of which is to begin a public relations campaign in which you begin to make the health community and the public aware of the need for health information flow and the good it can do. So, when you do develop the system, there is a relatively educated, favorably oriented group of people who are going to be participating in the system. I think this is a fairly critical step.

Then, we must assess technological impact. One thing I have not heard too much about in the last few days is, down the road, I think this system, if it actually came to pass, would have a profound impact on the way health care is practiced in this country

Mr. **Brown**. We hope so.

Dr. **Duncan**. I do, too,

Just one sort of medium range thing that is of concern to me is that when these computerized decision aides become available—and I am convinced they are going to come into being, because there are many people working on them, although still in the research laboratories and academic centers—we are going to be very much in line for nonphysician primary care.

At the same time, in this country we, are now in the process of producing, I think it's commonly known, an oversupply of physicians who are trained in traditional methodologies. What are you going to do with all these physicians? Are you going to hold back the technology or retrain the physicians, or what? These are very serious problems.

Of course eventually we will be, obviously, influencing medical eduation and will not be producing physicians who are not technically oriented. But for the next 30 years or so, this is a serious problem.

So, technology assessment is going to be a very big task the planning group has to see to.

And finally, the last step is to select the conceptual approach for CHIS development and implementation. This is the point after which we begin the traditional systems design, analysis, and implementation steps, but not until we're at that point.

I have just two final comments. Besides paying very careful attention to the kind of planners you select, you must make sure, as I have said before, that the planners are truly representative of all groups that are going to be affected and that they are experienced people who are already experienced in the important areas.

The second comment concerns placement of the system. Without question, it has to be a public/private venture. The Federal Government and especially the Congress, in its wisdom, is a group that has repeatedly concerned itself with these overview sorts of issues.

The impetus and push is going to have to continue to come from them, but the planning and shape of the system itself is going to have to be based in the arena of the consumers and providers of health care. One possible option is something like the Institute on Information Policy and Research, which I know you are considering now.

I think it is an excellent idea to have this Institute; my own concern about basing the CHIS planning effort in it is that there are so many technology issues that that Institute will be addressing that health information systems might get lost in the shuffle.

But clearly, an independent planning agency, in which all interests can be served is called for.

Finally, what we need are time, money, and national commitment.

Thank you.

[The prepared statement of Dr. Duncan follows:]

PLANNING AND RESEARCH AGENDA
for a
COORDINATED HEALTH INFORMATION SYSTEM

Karen A. Duncan
June 4, 1981

INTRODUCTION

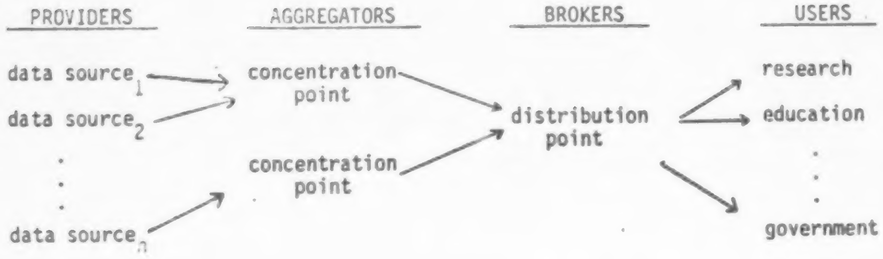
The need for coordination of health-related information at all levels - local, regional, state and national - is apparent in virtually every aspect of health care planning and delivery. Those arenas of health care that are not being developed as rapidly or as well as might otherwise be the case if there were an open and coordinated information flow include[1,2,3]:

long-range planning and policy formation
monitoring and assessment of Federally funded programs
monitoring the impact of environmental and workplace hazards
assessing the value of new technologies and drugs
epidemiology and public health
clinical research
health services research
cost containment research
health education
quality assurance
cost containment and reimbursement.

A close consideration of this list shows us that much of the needed information already exists - in forms ranging from raw data of unknown quality in patient records in basements of hospitals through the relatively sophisticated high-quality databases of the Federal government to published and accepted findings of a factual nature. Our task, then, is to find an effective and affordable way to bring our information resources to bear on the health and medical care delivery problems of our nation.

The general concept of finding solutions to these problems by improving information flow is what we are calling the Coordinated Health Information System (CHIS) concept. A truly effective and therefore valuable CHIS can be thought of as a model involving providers - or sources - of information, ways to aggregate, evaluate, and analyze that information, a means of disseminating the available information appropriately and, most of all, a need for the information. Of course the driving force for the model is the need, perceived a priori, for information such as might be provided through the CHIS. Naturally, the model would be very complex, involving an infrastructure, many feedback loops, and a set of rules for each function. A very simple schematic of the model is shown in Figure 1[1].

Figure 1. The CHIS Model


PROVIDERS
AGGREGATORS
BROKERS
USERS
data source$_1$
data source$_2$
data source$_n$
concentration point
concentration point
distribution point
research
education
government

CHIS ISSUES

Achievement of a CHIS is a very complex and costly task requiring skills and other resources that aren't readily available and/or acceptable. A CHIS would encompass not only the technical and logistical aspects of acquiring, analyzing, aggregating, maintaining, updating, brokering, retrieving and delivering a vast amount of diverse information in useful form, but also all of the attendant financial, managerial, political, sociological, and social ramifications as well. Thus a CHIS would be as much a new social institution as a new technological entity. Since the potential benefit of a CHIS would be enormous, it is well worth our while to invest in the extensive thoughtful and careful planning and research needed prior to development, in order to insure successful implementation and optimal long-term benefit.

Some of the major issues that need to be well-considered in advance are the following[4].

1. What are the possible logical architectures of a CHIS? To what extent should it be a single hierarchical physical entity vs. a loosely coordinated collection of resources and mechanisms?

2. A logical database must be created that can anticipate a wide range of future needs for information and analysis. For optimal value the database must make available demographic and environmental information as well as medical, health manpower, and health facilities information. But because of organizational and cost constraints, some limits must be imposed. Who or what groups will decide which information should be available, and in what form? How can value be assigned to various information elements to insure the design of a high-quality database that will meet future needs?

3. Some of the diverse necessary sources of information for a CHIS are hospitals, clinics, HMOs, nursing homes, insurance companies, and local, state, and Federal agencies. What mechanisms are possible for quality control? Can standards be agreed on? Imposed? Can information have value without standards and mechanisms for monitoring compliance?

4. Presumably the customers of a CHIS would include Congress, Federal agencies, local and state governments, other planning groups, private foundations, third party payors, researchers, clinicians, educators, and the public.

How can a method be implemented to broker the information available through a CHIS? Who should decide who may have access to which information for what purposes and at what cost[5]? This is a practical as well as a privacy question.

5. Would the automated aspects of a CHIS be able to provide adequate confidentiality and physical security of the information resource? What assurances would be necessary, to protect the national investment?

6. A sufficient pool of skilled health computing administrators and health computing technical specialists that can conceive, plan for, design, develop, implement, and administer a CHIS does not exist[6]. How can these people be recruited and/or trained? In addition, is there a sufficient pool of epidemiologists, biostatisticians, and systems-oriented physicians?

7. The unilateral or fragmented efforts by some agencies (e.g., HCFA) to establish elements of a CHIS have both cost and organizational implications[7,8]. Are these efforts detrimental to the orderly achievement of a unified and coordinated CHIS?

8. What impact would the free-flowing information have on the organizational structure of the health care delivery system? How will it impact the sociological and political structure of medical care[9]?

9. Where should the planning and research functions of a CHIS be placed? In a Federal agency? With the States? In a

new Institute created for that purpose? Through contracts or grants? Private foundations? Should the initial work be funded and/or carried out with public monies, private, or both?

10. Where should the control of a CHIS lie? Should it be public or private? Is participation voluntary or required[10]?

PLANNING AND RESEARCH AGENDA

The following section develops a list of critical planning and research activities for examining and resolving these kinds of issues. The activities must precede the successful implementation of a CHIS. The list of activities, including initial design activities, is summarized in Table 1.

1. ASSESS AND PRIORITIZE NEEDS

It is important to keep in mind that we're talking about more than just a statistical reporting system. It is natural that this would be seen to be the area of greatest need within the Federal government. However, academicians might feel that such information resources as NLM's MEDLINE will advance medical practice best. Similarly, some clinicians - and undoubtedly most consumers if they understood the potential - would argue for the National Medical Information System as proposed by Dr. E. R. Gabrieli[3] as being most valuable to them. Thus a major task of a planning commission would be to create or perhaps design ways of measuring "value" of services that might be provided through a CHIS in order to prioritize future steps.

Table 1. Planning and Research Agenda for a CHIS

1. ASSESS AND PRIORITIZE NEEDS
2. INVESTIGATE SOCIOLOGICAL, POLITICAL, AND PROFESSIONAL BARRIERS AND ISSUES
3. REVIEW STATUS OF TECHNOLOGY AND DEVELOP LIKELY FUTURE OPTIONS
4. STUDY PROGRESS AND RESULTS OF CURRENT PROJECTS THAT ARE RELATED TO CHIS CONCEPTS
5. DEVELOP CONCEPTUAL MODELS
6. DESIGN STUDIES AND DEMONSTRATION PROJECTS TO TEST THE ALTERNATIVE MODELS
7. RECOMMEND CONCURRENT PROTOTYPE ACTIVITIES
8. ASSESS TECHNOLOGY IMPACT
9. SELECT CONCEPTUAL APPROACH TO CHIS DEVELOPMENT AND IMPLEMENTATION
10. CREATE CONCEPTUAL SYSTEM DESIGN
11. DEVELOP FUNCTIONAL SYSTEM DESIGN
12. ESTABLISH FEEDBACK, REVIEW, REASSESSMENT, AND MODIFICATION MECHANISMS

It is important that the planning group start not with the concept of data needs but of information services. This is because, over time, information needs will change as many of today's most important health care delivery questions are answered. Also in time, as patterns of health care delivery change, the best sources of different kinds of information will change. Thus the assessment of need - and indeed our system design itself - must be generic, providing a framework and mechanisms within which specific but changing information flows can be achieved.

2. INVESTIGATE SOCIOLOGICAL, POLITICAL, AND PROFESSIONAL BARRIERS AND ISSUES

Sociologically, the advent of a CHIS of the kind we have been discussing has implications that have never been explored and are just beginning to be understood and considered. They are similar in many ways to the relinquishing of privacy that the information age brings to citizens in all areas of their lives as a by-product of its benefits. The nature and extent of these impacts need to be recognized, evaluated and perhaps mitigated.

Similarly, if the CHIS is carried to its fullest realization, it could have a profound impact on the way medical care is delivered in this country. As we develop the CHIS concepts and this impact becomes evident, polarization and resistance to change may be forthcoming from many professional groups. A subtle tendency to maintain the status quo is already apparent among some important professional associations, as demonstrated by their unwillingness to participate officially in investigating the potential and encouraging the development of the technology[11].

In order for a CHIS to be a positive force in the health care delivery system, it is essential that all concerned and affected groups perceive its positive potential and work cooperatively together to achieve it. To accomplish this harmonious development the planners will need to understand thoroughly and contend with these barriers and issues.

3. REVIEW STATUS OF TECHNOLOGY AND DEVELOP LIKELY FUTURE OPTIONS

Although in many ways a CHIS is a concept rather than a technology, certainly technology will play an extensive role in the realization of that concept. Thus the planners must investigate available technologies - particularly communications technologies and methodologies, architectures and software related to databases and information systems, and hardware and software for human-machine interface.

In addition to reviewing currently available and developing technology, the planners will also want to develop likely future options for technological development, as a necessary antecedent to later selection of technological options.
One of the most critical gaps will be found in the software for evaluation, interface, and delivery of information.

These problems are due in part, for example, to the primitiveness of our artificial intelligence techniques, our limited ability to process natural language, and our lack of understanding of human thought and learning processes and of likely future information needs.

A major design feature is the need to allow continual change in both sources of information for the system and groups that will use the information - and also in the information that established groups will need.

4. STUDY PROGRESS AND RESULTS OF CURRENT PROJECTS THAT ARE RELATED TO THE CHIS CONCEPTS

In many quarters of the nation we see activity that could be regarded as building blocks in creating a CHIS. Examples illustrating several aspects of a CHIS are mentioned here to show their value for study.

Many researchers have developed medical knowledge bases that are the kind of tool that's needed to pioneer the use of automation directly in medical practice and medical and allied health education, in addition to clinical research. There's also been an encouraging increase in interest in hospital information systems. Although current commercial offerings are based largely on - if not actually developed with - concepts of technology and systems and medical information needs that are 10 to 15 years old, they have provided us with many impartant lessons and - most important - they have done much to provide computer literacy to the health care community.

Professional and trade associations such as the American Hospital Association are developing databases and arranging for sharing data to meet their constituents' needs. Several large group health insurance underwriters have formed the National Electronic Information Corporation to serve as a cooperative claims clearinghouse. Concepts of compliance, quality and cost will surely be tested in these arenas.

Other valuable lessons come from the large-scale database development and distribution projects supported by the National Library of Medicine such as MEDLINE and the former Lister Hill National Center for Biomedical Communications Network. Because these systems operate in the realm of discrete "factual" information, controversial issues such as privacy and ownership of data have not been so significant. These experiments will be able to provide us with experience in marketing and distribution and in database design. On the other hand, the State of New York Health Care Data System provides us with a revealing look at the societal problems and the impact of such a system on the professionals of the health care delivery system[12].

Two systems being developed by the Federal government could each actually be a small-scale CHIS, when they are completed. Although medical education and research are not among its primary missions, the military's TRIMIS system provides us with an interesting study in the merits of a bottom-up approach to developing an integrated large-scale health information system. By contrast, the Veterans Administration's Health Care Information System is being approached with a top-down planning effort and a bottom-up implementation scheme. This style, too, provides us with an interesting case study.

Within the DHHS, HCFA's charter is so broad that it has concluded that it must implement an actual hardwired network linking it to all its data sources throughout the country. According to Kaple, "HCFA is in the process of planning and procuring a nationwide telecommunications network to facilitate data transmission between HCFA's central office and field sites" and "A major objective of HCFA's data communication plan is the consolidation of data transmission capability into a single configuration dedicated solely to HCFA's data communication requirements."[8]

HCFA's interests and concerns for information flow are vast, and its information systems are directed almost exclusively toward meeting its own needs, which in the context of the health care delivery system are primarily administrative. Its information systems are no doubt necessary, and we applaud HCFA's aggressive search for solutions to its needs. But it does prompt us to consider the long-term consequences of today's multiple disparate national health-related information systems. What about the rest of the health care delivery system? The medical side? Using HCFA as an example, when HCFA's hardwired telecommunications network is complete, are we going to build a separate parallel hardwire network for medical needs, for monitoring, for quality assurance, education, research, and policy in these areas? Or are we going to piggy-back on HCFA's network? Will it have the capacity for us to do so? Is its technology sufficiently advanced for our needs?

In summary, then, it appears that current efforts such as those named above are directed toward special interests - but appropriately so. Further, it appears to me that those areas that are being addressed on a large-scale level, such as technology, are experimental or developmental at best, and there are coordination problems and duplication of effort in both the public and commercial sectors. Most coordination and implementation efforts I am aware of in the public sector are being carried out on a microscopic, or detailed, level. Such projects are currently of interest primarily as learning experiences, though undoubtedly these same groups will be important providers, facilitators and users of a CHIS. The major problems of coordination and concepts of aggregation and brokering and manpower and cost are just beginning to be realized and are not being addressed at all in any effective manner.

The task ahead is formidable, so the planning group needs to take maximum advantage of the lessons of the past and present, as provided by current projects.

5. DEVELOP CONCEPTUAL MODELS

Notions of how a CHIS might look range all the way from maintaining the status quo, in which coordination is simply discussed, to the extreme of envisioning all health-related data residing on a single physical database. Undoubtedly the actual system that evolves will be somewhere in between, and its physical structure will be highly dependent on the available technology. Whether one thinks of a CHIS in which most data are physically commonly located, or whether one thinks of such a system in which each of thousands of collection points around the country maintains its own databases, the major problems still lie at the point at which data need to be brought together, evaluated, integrated, analysed, abstracted, updated, formatted, and delivered to the appropriate requestor (whose credentials for access would also have to be checked in advance) in an appropriate useable format in a manner that is timely for his or her needs. Location of the data seems almost irrelevant in the face of these concerns. Thus a conceptual model would deal more with the rules for melding and using data than with concern for how it is to be stored and routed.

Conceptual models would also have to include notions of security, confidentiality, updating, cost and charging mechanisms, rules for brokering data, and ways to assess the quality of data in order to guarantee its value.

Other concepts to be explored would include how to fund development and implementation, questions of ownership of information and control of access to it.

6. DESIGN STUDIES AND DEMONSTRATION PROJECTS TO TEST THE ALTERNATIVE MODELS AND GAIN ADDITIONAL INFORMATION

As a consequence of the planners' earlier work in evaluating technology options, investigating and assessing barriers, and studying current work, they would have had good preparation for identifying those remaining technical, sociological, and political areas that need further study before the final decision is made about the shape of the CHIS. Laboratories for the studies would be found in the commercial sector, the public sector, in academia, and among professional and consumer groups - in partnership among themselves and with elements of the health care delivery system. These studies and demonstration projects would be designed a) to fill the gaps in our knowledge or experience that were identified by the steps discussed above, and b) to begin merging some concepts in a test of the workability of aspects of the CHIS designs favored by the planning and design group. It is to be hoped that sophisticated computer tools for modeling and simulation will be available to facilitate these processes.

7. RECOMMEND CONCURRENT PROTOTYPE ACTIVITIES

Some activities will need to be carried out regardless of the final shape of a CHIS. One of these is the training of a cadre of multi-disciplinary individuals who are skilled and knowledgeable in the areas of health care delivery, sociology, information technology, and systems theory, and who can conceptualize, design, develop, implement, and direct the many aspects of a CHIS. We must initiate, now, educational programs for development of the necessary large pool of such professionals - health computing specialists[6]. Wide-spread education of the professional health community and the public should begin now, too.

8. ASSESS TECHNOLOGY IMPACT

A system as intricate and complex as the conceived CHIS, if effectively implemented, could pave the way for marked change in our concepts of health and health care. For example, as such an information system becomes one of the generally available information systems in our society, consumers will be able to access health databases through their home communications systems, so we are going to see a trend toward increasing self-care. It will also be within our power to deliver primary care - with the assistance of computerized knowkedge bases - at the non-physician level, so a logical evolution is for the typical physician of the future to be a medical or health computing specialist or researcher. But the scenario is at odds with the over-supply of physicians that will be practicing in the United States over the next 30 years. How should this be resolved?

This kind of long-range impact on health care professionals, and the attendant impact on health care facilities, insurance companies, etc., must be assessed and accounted for in the CHIS design.

9. SELECT CONCEPTUAL APPROACH TO CHIS DEVELOPMENT AND IMPLEMENTATION

At this point it would be appropriate for the planning group to make definitive recommendations and for the United States to make definitive commitments. Major decisions will relate to funding and control. Also, clearly, the the plan must be sufficiently flexible to take advantage of (or weather, if that is the case) any unforeseen future circumstances. Naturally the system must also permit continued evolution in sources of information and in information needs.

10. CREATE CONCEPTUAL SYSTEM DESIGN

This design step is essential for providing a framework within which all development activities must fall. It is listed here because it will occur in part concurrently with final planning activities, and probably will be guided by the same knowledgeable group of people. The design would include plans not only for physical model implementation, but also for establishing liaisons, creating funding resources, providing education and re-training, facilitating use of the CHIS, etc.

11. DEVELOP FUNCTIONAL SYSTEM DESIGN

This is the final step, after which the work of implementation is segmented, or modularized, and carried out with strong central guidance. This step, too, is listed here because of its close ties with planning.

12. ESTABLISH FEEDBACK, REVIEW, REASSESSMENT, AND MODIFICATION MECHANISMS

A project of this scope will require a concerted effort to keep it on track over the many years of its development through changes in the economy, evolving technologies, and shifting national priorities. Mechanisms to achieve this should be built in during the planning stages.

REQUIREMENTS FOR PLANNING

As has been stated often, planning and development of such a complex system as the one we have been discussing cannot be left to chance. Those who are working on coordinating pieces of the system today can at best be working on a bottom-up approach to the total system - that is, the integration of disparate pieces. A CHIS, with its medical, technical, sociological, political, policy and managerial implications, is clearly an n-dimensional problem that requires a simultaneous look, or top-down planning. The ability to look at the entire n-dimensional problem and the intricate interrelationships requires unusual vision and skills.

How do we approach creation of a coordinated health information system? First we need blue-ribbon top-down guidance from experts with n-dimensional vision and a real and primary commitment to the planning process. It won't be a cheap or easy process, but it will in the long run be faster, cheaper and easier than the present undirected evolutionary path.

Then it is necessary to find a new framework within which such talented individuals can work to plan for and achieve a coordinated health information system. While many groups have made substantial contributions to the concept and background needed for a CHIS - and indeed we could not consider this enormous step today without climbing on their shoulders - planning and development of a system that has such extensive ramifications should be done apart from, but in cooperation with, those who have an interest in some smaller part of the system. The proposed Institute for Information Policy and Research might be an appropriate place for the planning activities.

Third, we need funding for initial planning and related activities. Fourth, and most inportant, we need a national sense of the urgency and importance of the project, and a commitment from all quarters.

The primary planning effort should be the responsibility of highly qualified professionals who would devote their primary energies to this project for several years. Advisory panels to provide perspective and guidance, and a close relationship with all concerned groups, would be needed. Even in the planning phases, cooperative efforts in the public and private sectors are recommended, to develop vital linkages and identify funding for projects of mutual interest.

If there is adequate funding and other support for the planning effort - including funding for appropriate demonstration projects and testing of policy alternatives - the planning group should be able to present its definitive design in five years. Completion of a prototype - or Phase I - CHIS might be possible by the year 2000, at a development funding level equal to about 3% of our health care dollars.

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Mr. **Brown**. Thank you very much, Dr. Duncan.

Your paper, as a whole, I think raises all the very practical issues which are important to consider in thinking realistically about the changes that might be represented by CHIS.

Let me ask a question or two about the last point that you made. The mechanism by which we might start a process here, each of us who looks at this overall situation has a different idea what we're talking about.

As you pointed out in your statement, some are very fearful that this is another effort to set up high-level Federal controlled end plans which would take a lot of freedom away from the health community in this country. And there is some basis for that.

My own views tend toward a decentralized kind of a system, with progress at various stages and various areas, depending upon what the reasonableness of the benefits are. And basically I am concerned that we move toward the integration of all of the information resources available to us today, so as to have an overall impact on the health of the Nation.

I look at it in that sense, and I'd like to do it, of course, in a way that maximizes freedom of action and the local autonomy, not minimizes it. From that standpoint, it is essential that we have the cooperation of public and the private sector in some sort of a planning process. In wrestling with that problem on a general basis, we have thought of this Institute on Information Policy and Research.

But, as you point out, health information systems might be obscured in that and health information systems in themselves relate to what is now a sizable sector of the total U.S. economy.

We are talking about something approaching 10 percent, maybe more. And in that sense, you might be able to justify a separate cooperatively managed institute just for the health systems in themselves. I haven't thought about that in depth.

During the course of these hearings, it began to seem that that might be one mechanism. And I would like you, just off the top of your head, to comment about what the pros and cons of that sort of approach might be as an initial planning phase for something of this sort.

Dr. **Duncan**. An institute on medical information systems?

Mr. **Brown**. Yes.

Dr. **Duncan**. I think it's a very good idea, and as a watcher of the evolving approaches to the whole concept of health information systems like this, it seems to me that we are almost driven in that direction. We have not seen other approaches succeed. So an institute to focus specifically on that and perhaps, even more broadly, on health computer technology, as well as information systems—an agency or institute that is specifically charged with that—yes, I think it's an excellent idea. I would like to see it.

And, as you say, the health care dollar looms so large in our lives now, I think we cannot advance medicine much further than we have until we open up information—the information flow in the system. And we must.

Mr. **Brown**. I was rather interested in your table 1, defining research in general for CHIS, which you went over—and if you would take CHIS away from that and describe the process of development in a rapidly changing technological society, that it would apply to the whole thing.

Dr. **Duncan**. Yes. I was hard put to be original, because what we clearly need is top-down step-wise planning of this sort.

Mr. **Brown**. Mr. Scheuer, do you have any questions of Dr. Duncan?

Mr. **Scheuer**. Well, your testimony was most thoughtful, Dr. Duncan. You asked an awful lot of questions and very good ones, and you laid before us some of the problems and the roadblocks and some of the human engineering that has to be done.

What we need, I think, as Congressman Brown has alluded to, is a sort of step-by-step process to the extent the Congress can help move it all forward, and it's perfectly clear that a lot of initiatives have to come from the private sector. We can't do it all.

You have mentioned on page 7, where you say "CHIS is a concept, as much as anything else," and you talk about a subtle tendency to maintain the status quo already being apparent in some important professional associations, as demonstrated by their unwillingness to participate in officially investigating the potential and encouraging the development.

You say it's a concept, rather than a technology. And we do have a human problem here. You say it's essential that all concerned and affected groups perceive its positive potential and work cooperatively together to achieve it.

What is the process by which we can try to achieve some consensus among the important institutional groups, like the AMA and the American Hospital Association and the State organizations of doctors and hospitals and clinicians? What is the process—the learning process—by which we solve this human engineering or human interface problem that you are talking about? How do we create a system or a process in the private sector that over a period of 3, 4, or 5 years of investigation and study and seminars and outreach, we can begin to achieve some consensus out there that CHIS was not a threat but a boon. That it offers institutions and individual clinicians, individual practitioners, a chance to achieve a high level of professional excellence, and that it's an enhancement process and not a demeaning threatening process.

How do we get from here to there?

Dr. **Duncan**. Well, I'm glad you asked me that.

The first thing you said was needing initiative from the private sector. And this is something that I come to the conclusion that you're not going to see, which is why I made the comment I did about the reluctance in the professional agencies.

In terms of getting the national cooperation, I see it as a public service campaign, very much like the antismoking campaign. I can envision ads on television, continually—continually a message being sent out to create a change in attitude toward health information use and flow.

Now, obviously, there has to be a group charged with doing that. There has to be some national commitment that we're going to undertake this.

So, I would see this institute that you're talking about charged with more than planning and research—having a specific charge to begin activities that will create a positive environment for a CHIS.

The Government, even when it is reluctant, having realized that something has to be done that isn't coming from anywhere else, has done it. You have changed the attitudes about smoking and you have changed people's health habits. But it has not been the AMA that has done so. It's been other groups. And I think the same thing is going to have to be done here.

Mr. **Scheuer**. Except with smoking, we began to change individual behavior among 25 or 30 million people.

Smoking and dietary habits. There has been a change in the last decade. The consumption of fats and butter and sugar and so on and so forth. There has been a change. Somehow or other, we have been able to reach the masses. Here we're not talking about any public relations program to reach all the American people. We are talking about some kind of an outreach to encourage change in the attitude of decisionmakers in the medical fraternity, associations, individual practitioners, et cetera.

And that's less a matter of advertising on television than it is direct outreach to people who are making important decisions about whether or not individual practitioners or hospitals or major health associations are going to cooperate and involve themselves in devising a system that serves the interests of the national Treasury, the taxpayers, and the institutions themselves.

How do we fine tune this process?

Dr. **Duncan**. Well, I'm not sure that the process is that different. We have over 10 million health care professionals in this country that work in the health care delivery system. And if you consider all the clerical and other trades and what have you, it's more than that. So we're not just talking about physicians. It wasn't the doctors alone that made the decisions about today's hospital systems. And to make them succeed it took the cooperation of the nurses and administrators and so forth.

The other thing is I think doctors are very much tuned to their social environment. We're talking about, say, a 5-year change. Now, in a 30-year change, we know we can change physician attitudes through education in medical schools. But we are talking about trying to turn people's attitudes around in the next 5 years. I think there are tremendous consumer pressures on physicians to be more favorable toward computer technology. Possibly it's one of the most effective short-range tools you can use to influence physicians thinking about something.

Mr. **Scheuer**. Can you elaborate on that? I'm not familiar with consumer pressures.

Dr. **Duncan**. It's not something that's been used very much on the medical profession.

Mr. **Scheuer**. Does it exist, really?

Dr. **Duncan**. Consumer pressure? No, not today.

Mr. **Scheuer**. We believe that the HCFA has made significant progress in developing the CHIS. Incremental steps have been taken. Could you comment on this effort? And especially with respect to what ideas you might have about further planning and development?

Dr. **Duncan**. Well, the HCFA system is an interesting one. I understand that they are, in fact, planning to develop their own nationwide hardwired, physical network to meet the extensive needs that they have for information.

One thing I think has to be realized about the HCFA system is that the data they use is primarily administrative or management, as opposed to medical, or patient care oriented, apart from the quality assessment program.

But I did have some question about that in my paper. If HCFA puts in it own network, then supposing we want to do something about the medical side of the information or collect some other statistics. Are we going to put in a second network, parallel to HCFA's, to all hospitals or wherever it's going to go? Or are we going to share HCFA's network? And if we are, does it have the capacity to handle all these other needs we're talking about?

I applaud what HCFA is doing and I know we can learn a lot from them. I admire their aggressive approach to meeting their own needs. Nonetheless I would like to see where what HCFA is doing fits into the context of what the rest of us perceive as needed, also.

Mr. SCHEUER. In other words, what you're saying, if I can interpret your words, is that HCFA is concerned with health care costs—a cost control program. But in addition to that there's a whole question of degree to which the computer can assist the physician in fine tuning his diagnosis and his patient care. And, I take it, you're saying how do we get HCFA or how do we make HCFA's system compatible with expanding it to also include medical care information and help the physician improve the quality of both diagnosis and subsequent treatment?

Dr. DUNCAN. It's not so much how, but should we do it. Can we do it? These are all questions that the planners would have to consider.

But the fact is that HCFA is a case in point of what is going to happen as people do get frustrated because their needs are not being met. They are going to go out and develop their own network, getting their own data.

Of course, you have that situation now with the Federal Government, but you are going to have it on a national level in the medical area as well as the Federal.

Mr. SCHEUER. Well, you're suggesting that HCFA alone is not creating a system that will do the whole job?

Dr. DUNCAN. It's a drop in the bucket.

Mr. SCHEUER. It's a drop in the bucket?

Dr. DUNCAN. It addresses their needs.

Mr. SCHEUER. Looking across the whole spectrum of the Federal Government, is the existing organization and mission orientation of all of the Federal agencies that are involved in collecting health data taken together?

Dr. DUNCAN. Are you asking, can they respond?

Mr. SCHEUER. Well, what I'm saying is the present elaboration of health care agencies, with the current ways in which they're elaborating their systems of data collection, taking it all together, is that an institution or a framework that can respond to the congressional mandate for better coordination of health care data?

Dr. DUNCAN. From my perspective, the totality of the Federal Government data collection activities are a special interest only—

and a very important one—that has to be served by the Coordinated Health Information System. But it is only one. It is not a framework; it's a piece.

Mr. SCHEUER. What exists now is not the framework? It's a piece.

So, in effect, we have to get some kind of superstructure in which existing elements each have their place, but where we fill in the gaps, I would take it?

Dr. DUNCAN. This is what I believe.

Mr. SCHEUER. Can you give us a step-by-step incremental program by which we achieve that?

Mr. BROWN. That's on page 6.

[Laughter.]

Dr. DUNCAN. Do I have one minute or two to do that in?

I really think the starting point is, in fact, some sort of planning commission within the context of an institute. I think it's got to be broader than any particular Government agency. It's bigger than that, especially when you take into consideration the medical component.

If you can identify a group of planners to serve within the institute and give them very specific charges—at this point, I don't this coming anywhere but from Congress—very specific charges to begin an educational program and to begin the very steps that I outlined earlier, identifying needs, identifying issues, developing a value system within which we can compare needs, then well eventually have a CHIS.

It's obvious we're not going to do everything at once. I think the very first step is the planning and education process, to begin with an institute or something that will allow planners to have a place to work.

Mr. SCHEUER. You are, in effect supporting Congressman Brown's initiative?

Mr. BROWN. She's already stated she thought it was a very fine initiative.

[Laughter.]

Mr. DUNCAN. Yes.

Thank you very much.

Mr. BROWN. Thank you very much, Dr. Duncan.

We have no exhausted all of the questions that we have prepared for you and hope we can call on you later.

At this point, I would like to indicate that I am the chairman of neither of the subcommittees conducting these hearings, and I would like to turn the chair over to Mr. Scheuer, who is chairman of one of the subcommittees, and who I think had some comments he would like to make. We do this symbolically.

Mr. SCHEUER. The next witness is Dr. Edward N. Brandt, Assistant Secretary of Health for the Department of Health and Human Services.

STATEMENT OF EDWARD N. BRANDT, JR., M.D., PH. D., ASSISTANT SECRETARY FOR HEALTH, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. SCHEUER. Dr. Brandt, we are very happy to have you here. We do have some concern over the fact that we didn't receive your testimony until after the hearing had started this morning. As a matter of fact, I haven't seen it yet. It was distributed to the press before it was distributed to the members of the committee. It hasn't yet been distributed to the members, so I would be reluctant to have you deliver your testimony before I have had a chance to analyze it, without knowing that I'd have a chance to chat with you and ask you some questions at a later date.

In other words, if you can tell us that you would be willing to come back here in the next week or two, on a day convenient to you, I'd be happy to have you chat with us today. But I am not prepared to hear your testimony today if I'm not going to have another opportunity to ask you questions.

So, why don't you tell us what your wish is? We can either excuse you now and arrange another date for you to come back, during which time we can have a chance to study your testimony, or if you will assure us that you will come back in another week or two, at a convenient time, then we'd be happy to hear you today.

Dr. **Brandt**. Well, I apologize, Mr. Chairman, if you did not receive an advance copy. The letter inviting me did not indicate that one was desired, and so, in fact, we didn't send one. I will be happy to come back at sometime subsequent.

Mr. **Scheuer**. As I understand it, our staff people have been in touch with your staff people for the last week inquiring when the testimony will be available.

Dr. **Brandt**. That could be.

I will be pleased, in any event, to come back at a subsequent time.

Mr. **Scheuer**. Then, why don't you proceed any way that you wish. I still don't have a copy of the testimony here. You can either write it, read it, or if you prefer, you can summarize it and hit the high spots. You might also avert to anything you have heard here this morning, either from other witnesses or the members up here, or any testimony that has been given earlier this week.

Feel free to take us to the mountain top and give us your overview of the elaboration of the information services, what are the problems, what are the difficulties, and what is the ultimate potential?

Dr. **Brandt**. I will be happy to go over and hit some of the highlights of the testimony, which is fairly detailed, with respect to some of the activities of the Department of Health and Human Services, and specifically the Public Health Service and the issue of health data.

It is a pleasure for me to be here with you today. The last time I appeared before this committee, in 1978, the scope of your deliberations was considerably narrower, specifically dealing with "computers in health care."

At that time I was with the University of Texas. And since that time my vantage point has changed and there have been a number of changes also in——

Mr. **Scheuer**. There has been a national change in management. [Laughter.]

Dr. **Brandt**. Yes, sir. I'm very much aware of that, sir.

A great deal of progress has been made within the Department and throughout the country, I think.

I would, first, like to look at the issue of the concept of the coordinated health information system as things stand today. The United States is certainly one of the world leaders with respect to the scope of its health data system, and the technical competence with which it acquires, processes and tabulates information.

The Department of Health and Human Services is the principal public health sponsor of national health statistics activities, and, therefore, our Department's activity comprises the keystone of the National Health Statistics and Information System.

One of the most significant challenges in the field today continues to be the development of responsive health data systems, capable of satisfying the multiple needs for data at various levels and for providing the data needs for national health policy development.

We turn now to the specific aspect of the coordinated health information system. We have reviewed the proposal sent by the staff of the subcommittee, which describes the need for and the function of such a comprehensive coordinated health information system.

The document expresses an idea which on the surface is very appealing. However, if examined more closely and compared to our current experience, its feasibility and cost-effectiveness are both uncertain. The major error made in proposals for coordination of medical data is to underestimate the difficulty in translating the technological success in confined, controlled situations to larger undertakings.

The difficulty increases geometrically as the scope of the project, the number of participants and data items increase. This applies to all aspects of the system.

For example, the ability to have one hospital agree on and carry out a uniform numbering system that gives a patient the same number each time the patient comes into the hospital is achievable, both in practice and concept. But as the coverage is broadened from a single hospital to all hospitals in a city, State, and nation, irrespective of the sponsorship, the ability to accomplish that task, and the acceptability of the idea, diminish greatly.

Another point concerns the scope of the system——

Mr. SCHEUER. Excuse me. You said "irrespective of" what?

Dr. BRANDT. Irrespective of the sponsorship of the hospital.

Mr. SCHEUER. Yes.

Dr. BRANDT. Another point concerns the scope of the system as it affects its ability to function. As the system expands geographically and in information content to meet the inevitably increasing demands, it becomes more difficult for the people operating the system to be responsive to individual user needs. The size of the system in itself dictates certain conventions and procedures which will limit access to the data and lessen its unique applicability to any one user.

Given the fact that this concept is still developmental, it's difficult to be specific in covering costs. But our experience with very limited comprehensive systems makes us very concerned as to the resources that would be required to institute a coordinated health information system. This concern is accentuated during a time of necessary fiscal restraint.

In essence, provided that such a system could technically be developed, the question of whether we should be pricing the gathering of pertinent data outside of our available resources becomes a critical issue.

Quality and usefulness of the data contained in a coordinated system is of great concern to me, both as biostatistician and as one concerned about the development of the future health policy in this country. The development of common definitions and vocabulary, two factors key to quality data submission, take years of advance work prior to actually including the data in a system.

It takes years of advance work prior to actually including data in a system. We have been working, as an example, for several years with the health issues along the border of the United States and Mexico. And I met with my counterpart from Mexico this week. We still have not agreed to a common definition and standards for data between ourselves and Mexico that will allow us even to measure the magnitude of the problem or set the priorities in the border region. We are making progress, and I don't mean to imply that we are not, but it is difficult.

And when we began to look at the full range of health care data that is maintained by the U.S. Public Health Service, which covers the full range, it becomes even more difficult.

The National Center for Health Services Research, currently developing a chronic disease data bank, is experiencing such problems at this time. For every diagnostic category, we must determine the significant data set. To expand this to all diseases poses potentially enormous problems.

Furthermore, standardized definitions and standardized data sets may stifle innovation and actually interfere with the recognition of new diseases or heretofore unrecognized manifestations of known diseases.

Another concern that I have deals with types of data that will be included. For example, information on marital status and personal habits may be important in formulating disease-specific diagnoses, but the accumulation of such information for less specific future and as yet undefined purposes may raise serious questions about the relationship between society and the individual.

Furthermore, maintaining changes in information on habits such as quitting smoking may not be available on a timely basis and therefore may actually interfere with our ability to use the system in a meaningful way.

Obviously, such data systems raise all sorts of questions about privacy and confidentiality, and would require that necessary safeguards be implemented.

In summary, I certainly recognize the proposed benefits of a coordinated health information system. But the concerns that I have raised in the experiences of the Public Health Service lead to the conclusion that the feasibility, in terms of technical capability cost, data quality, and appropriate confidentiality and protection of the American people, is yet to be demonstrated.

Our inability to construct such a system at this time, however, does not mean that we in the Department are not addressing issues of concern to all of us as to effective planning for statistical activities, including the setting of priorities, coordination, and elimination of unnecessary reporting burdens on the public.

The health statistics planning process has been going on since 1975 in the Department. Its goals are outlined in the testimony on page 8, and they, I think, cover the full range of activities that need to be addressed.

In recognition of the complexity and the widespread distribution of responsibility for health statistics systems, a health data advisory committee was established in 1979. This committee advises me and the Secretary on current and long-term health data needs, on policies and procedures for Department-wide coordination of health statistics activities, on proposals for major new health statistics systems, and on minimum basic data sets.

It, in fact, is the committee that insures a coordinated approach to health statistics data for the Department of Health and Human Services. It also deals with the Office of Management and Budget's Office of Federal Statistical Policy and Standards, the Department of Defense, and the Veterans Administration as well.

This committee is responsible for overseeing the development of the Department's annual health statistics plan, and I have brought copies of that and copies will be made available to you, as well as the "Health Statistics Inventory," which is also published on an annual basis and is a complete inventory of ongoing and planned health data collection efforts throughout the Federal Government.

In addition to this internal committee which monitors these activities and serves as a planning committee for health information collections within the Federal Government, we also have external advisory committees to assist us as well.

Internally, the Public Health Service and the Health Care Financing Administration (HCFA) have been cooperatively evolving programs relating to the mutual interests of both agencies in health information systems.

We have attempted to eliminate duplication, and have jointly allocated data areas and program interests. Duplicative systems are being eliminated; shared systems are being developed. These efforts to coordinate activities between HCFA and the Public Health Service are a major step forward and do provide us with new mechanisms and opportunities for integrating data from diverse sources.

In addition to the activities between the Public Health Service's total entity and HCFA, it's important to recognize that several operating agencies of the Public Health Service are also active. The Centers for Disease Control in Atlanta monitors a number of diseases around the country and publishes a weekly report on significant illnesses that is timely, that is up to date as of Tuesday of that week, and is published on Friday. CDC also has provision for transmitting this data by telephone link from the CDC computer to any State health department computer or any official agency within that State. They provide surveillance on a number of specific projects, such as toxic shock syndrome, Legionnaires' disease, and other problems that have developed.

Both of those I think present to us a classic example of how a rigid, overall-defined, comprehensive health information system would probably have prevented us from recognizing those two illnesses and from developing the cause and the appropriate treatment for both Legionnaires' and toxic shock syndrome.

The Centers for Disease Control has also expanded its surveillance efforts to include environmental health problems, toxic wastes, and dental disease as well.

The Food and Drug Administration, which is, of course, a regulatory agency concerned with consumer protection, does engage in special studies and data collection dealing with both nutrition knowledge and educational efforts, food additives, product labeling, and other activities which are important to the health of the public and, of course, have a major commitment to that effort.

The National Institutes of Health is the lead Federal agency for biomedical research. They collect data which is primarily related to research activities and have a functioning system that complements the search for the etiology of disease.

Within the Office of the Assistant Secretary for Health is the Office of Health Research, Statistics and Technology, which includes the National Center for Health Services Research and the National Center for Health Statistics. Each of these programs deals with activities directly relevant to the concept of a coordinated data health information system. Particularly, the National Center for Health Services Research has been active in funding research that is specifically oriented to the needs of such a program.

I could go on and talk about more of the coordination and integration that is currently going on within the Department and that is planned for the future. I can assure you that we are developing even greater plans to integrate these and to take a rational, reasonable approach to the integration of the data which serve the needs of those persons who are, in fact, concerned with health information.

That concludes my overview statement, Mr. Chairman. I will be pleased to answer any immediate questions you have and I repeat that I will be happy to come back at a future date to continue.

[The prepared statement of Dr. Brandt follows:]

DEPARTMENT OF HEALTH & HUMAN SERVICES Office of the Secretary

Washington, D.C. 20201

STATEMENT

of

EDWARD N. BRANDT, JR., M.D., Ph.D.
ASSISTANT SECRETARY FOR HEALTH
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

before the
SCIENCE, RESEARCH AND TECHNOLOGY SUBCOMMITTEE
and the
SUBCOMMITTEE ON NATURAL RESOURCES, AGRICULTURE RESEARCH
AND ENVIRONMENT
of the
COMMITTEE ON SCIENCE AND TECHNOLOGY
U.S. HOUSE OF REPRESENTATIVES
June 4, 1981

Mr. Chairman and Members of the Subcommittee:

It is a pleasure for me to join you today in the examination of the need for and the issues and problems associated with a systematic coordination of health information systems. When I appeared before this Committee in 1978, the scope of your deliberations was somewhat narrower: "Computers in Health Care." Several years have elapsed and certainly my vantage point has changed. Also what has changed is that a great deal of progress has been made since those hearings in advancing data system coordination in the Department of Health and Human Services.

Today, I would like to provide the Subcommittee with comments on the concept of a coordinated health information system, the data systems of the Department, and areas of coordination between those systems..

General Overview

The United States is often acknowledged as one of the world's leaders with respect to the scope of its health data systems and the technical competence with which its acquires, processes and tabulates data. Since the DHHS is the principal public-sector sponsor of national health statistics activity, the Department's activities in this area comprise the keystone of a national health statistics and information system.

We recognize that a comprehensive and responsive information base is an essential resource in health policy formulation and in program management and evaluation. Timely and reliable data are needed on the health status of the population, the availability of health resources, sources of funding and the quality and outcome of care rendered.

One of the most significant challenges in the field of health statistics today continues to be the development of responsive health data systems capable of satisfying the multiple needs for data at various levels and for providing the data needed for national health policy development. The increasing need for quantitative information coincides with increasing limitations on financial and personnel resources available to meet such demands and increasing public concern about the burden Federal reporting requirements place on the respondent.

At this point, I would like to turn my attention to the concept of a coordinated health information system or CHIS as referred to by some.

A Coordinated Health Information System - Areas of Concern

After reviewing a proposal for a coordinated health information system, which describes the need for and the function of such a system, I believe it necessary for the Department to offer comments on the feasibility of a CHIS. The document expresses an idea which on the surface is appealing. However, if it is examined more closely and compared to our current experience, its feasibility and cost-effectiveness are uncertain.

Technical Feasibility

The major error made in such proposals is to underestimate the difficulty in translating the technological success in confined, controlled situations to larger undertakings. The difficulty increases geometrically as the scope of the project, the number of participants and data items increase. This applies to all aspects of the system. For instance, the ability to have one hospital agree on and carry out a uniform numbering system that gives a patient the same number each time the patient comes into the hospital is achievable, both in practice and concept. However, as the coverage is broadened from a single hospital to all hospitals in a city, State and Nation, the ability to accomplish the task and the acceptability of the idea diminishes greatly.

Responsiveness

Another point concerns the scope of the system as it effects its ability to function. As the system expands geographically and in information content to meet the inevitably increasing demands for information, it becomes more difficult for the people operating the system to be responsive to individual user needs. Size of the system dictates certain conventions and procedures which in some cases limit access to the data and lessen its unique applicability to any one user. As the system increases in bulk, a decreasing percentage of information is used by any one individual. This increases the cost of each individual data item to the user and thus may create a disincentive for use of the system.

Cost

Given the fact that the concept of a coordinated system is still in a developmental stage, it is difficult to be specific in discussing costs, but our experience with very limited comprehensive systems makes us very concerned as to resources that would be required to institute a CHIS. This concern is accentuated during a time of necessary fiscal restraint. In essence, provided that such a system could technically be developed, the question of whether we would be pricing the gathering of pertinent data outside of our available resources is a critical issue.

Quality of the Data

The quality and usefulness of data contained in a coordinated system is of great concern to me both as a biostatiscian and as one concerned about the development of future health policy.

and vocabulary, two factors key to quality data submission, take years of advance work prior to actually including the data in a system. The National Center for Health Services Research, currently developing a chronic disease data bank, is experiencing such problems at this time. For each diagnosis, we must determine what is the significant data set. To expand this very limited data bank to all diseases, poses potentially enormous problems. Furthermore, standardized definitions and data sets may stifle innovation and actually interfere with the recognition of new diseases or heretofore unrecognized manifestations of known diseases.

Control of the System

Another concern I have about a CHIS system is the question of what types of data go into the base. For example, information on marital status and personal habits may be important in formulating disease-specific diagnoses, but the accumulation of such information for less specific future and as yet undefined purposes may raise serious questions about the relationship between society and the individual.. Furthermore, maintaining changes in information on habits such as quitting smoking may not be available on a timely basis.

Privacy and Confidentiality

Any discussion of such a system must consider fundamental issues of privacy and confidentiality. Organizational arrangements that make personally identifiable information more available for many desirable purposes have the potential for making this same information more generally available for other less clearly desirable purposes. It is this concern for the potential uses ofdata on specific individuals that has given rise to much public debate in the last several years -- a concern evidenced by Congressional hearings, Executive Branch deliberations and review by a national Privacy Protection Commission.

A centralized data system must be surrounded by legal and organizational safeguards, strict in design and credible to the public, to assure that information gathered for certain research purposes is not improperly used.

The research and statistical communities share these concerns and the Department is evaluating possibilities for appropriate control mechanisms. One such possibility is the Data Protection Review Board established by New York State to oversee access to the data base developed under the Health Care Financing Administration (HCFA) Integrated Data Demonstration grant. Experience to date indicates that it is feasible to concentrate person-specific information on all hospital patients in New York State in a single data base provided prudent and equitable safeguards are legislated to protect against unlawful access.

We are confident that we can work ultimately to accomodate both the larger research and statistical needs of individuals and the confidentiality needs of individuals.

In summary, while I recognize the proposed benefits of a coordinated health information system, the concerns I have raised lead to the conclusion that the feasibility, in terms of technical capability, costs, data quality, and appropriate confidentiality, of this type of system is yet to be demonstrated.

Our inability to construct such a system at this time does not mean that we are not addressing issues of concern to all of us as to effective planning for statistical activities,the setting of priorities, coordination, and elimination of unnecessary reporting burdens on the public. I am confident that much is already being done to meet the need for statistical information.

The Health Statistics Planning Process

Much of our current success in meeting this need for coordination stems from the initiation in 1975 of an organized health statistics planning process. This process reflects the Department's commitment to the continuing development of a balanced, compatible and useful health information and statistics system for the Nation.

The major goals of the Department's health statistics planning effort have been the development of coordinated health data systems that will:

- meet statistical needs for developing and evaluating national health policy;
- meet program management data needs for health programs of the Department;
- respond to Federal, State, local, and private needs for health statistics in a timely fashion;
- assure confidentiality of data and privacy of respondents to Federal health data collection activities while assuring availablility of appropriate information to the public;
- generate health statistics as efficiently as possible, with the least possible burden on the public;
- assure quality and accuracy of statistics;
- assure compatibility of statistics across the major Departmental data collection programs through standards where possible and promote record linkage among data files to enhance comparability and usefulness of data resources;

- assure maximum compatibility of statistics with major international, national, State and local health statistics systems.

A component of the Department's health statistics systems includes the internal and external advisory committees which address issues of statistical policy and coordination.

In recognition of the complexity and the widespread distribution of responsibility for health statistics systems, a Health Data Advisory Committee was established in 1979. The committee advises the Secretary on current and long-term health data needs, on policies and procedures for Departmentwide coordination of health statistics activities, on proposals for major new health statistics systems and on minimum basic data sets. The Health Data Advisory Committee ensures a coordinated approach to data-oriented health policy issues. Active participation of representatives of OMB's Office of Federal Statistical Policy and Standards, the Department of Defense and the Veterans Administration provides us with valuable information on related experience and data requirements outside of the Department.

The Committee is also responsible for overseeing the development of the Department's annual health statistics plan mentioned earlier. This year's report, Health Statistics Inventory: FY 1981, is an inventory of ongoing and planned health data collection efforts and is linked directly to the Federal Government's first Information Collection Budget. The Budget was developed pursuant to ExecutiveOrder 12174 which included several processes for reducing response burdens on the public.

The Inventory represents a departure from the planning procedures used in prior years. Earlier plans have been comprehensive in approach, containing a conceptual framework for the health statistical activities of the Department, a description and analysis of these activities, a discussion of cross-cutting issues in the Department's health statistical systems, a multi-year action plan, and an inventory of ongoing, and to some extent, planned systems and projects. These plans reflect the evolving nature of the Department's planning efforts in the area of health statistics.

The external advisory committee advising the Department is the National Committee on Vital and Health Statistics (NCVHS). This Committee advises the Department on a vast array of issues relating to health statistics such as data standardization, needs for statistics in specific high priority areas, issues of confidentiality and the report to the Congress, Health, United States.

One of the primary means of coordinating data systems is to ensure comparability of data. This is done through the development of standard concepts, terms, definitions, classifications, survey frames, procedures, etc. for the current function-oriented health data activities of the Department. A significant barrier to the comparability and usefulness of health data collected and analyzed by various programs, is the lack of common terms, definitions and classifications for the collection and analysis of similar data across programs. Such standardization is necessary for the derivation of adequate program monitoring and measurement scales. Interprogram comparisons and studies of program effectiveness are not feasible if data systems do not have a large measure of uniformity.

Several advances are being made in the areas of standards development and enhancement of comparability. The adoption by the Department of the International Classification of Diseases, Ninth Revision (Clinical Modification) (ICD-9CM) for diagnosis labeling for all relevant programs will enhance comparability of morbidity and mortality data.

Within the Department, the Public Health Service has begun a modest program of standards and guidelines applicable to all data collection. The standards were developed after an extensive review of over 100 major health data projects and systems within the

Department. The HDAC has now recommended implementation of these standards throughout the Department and for developing additional standards and guidelines.

Internally, the PHS and HCFA have been cooperatively evolving programs related to the mutual interests of these agencies in health information systems. Because of legislative mandates, independent pursuit of data collection could result in duplication, overlap, excessive cost and excessive public response burden. In response to these issues, cooperative action was taken to assure development of coordinated health information activities between PHS and HCFA.

In terms of elimination of duplication, HCFA and PHS jointly allocated data areas and program interest. Duplicative systems are being eliminated and shared systems are in the offing.

Going beyond the Department, the Paperwork Reduction Act of 1980 has major potential toward a coordinated Federal Health Information System. For example, this Act calls for the establishment of a Federal Information Locator System composed of a directory of information resources, a data element dictionary, and an information referral service.

These efforts to coordination health data gathering systems are a major step forward and provide us with new mechanisms and opportunities for integrating data from diverse sources.

However, it is important to realize that much of the data collected through Department systems is directly related to the program responsibilities within separate and unique agency functions.

These separate functions are related to the statutorily based responsibilities of these agencies, and maintaining the integrity of the data collected in conjunction with these responsibilities must remain a key priority within any overall system of data collection and coordination.

I would like to briefly highlight for you these unique agency missions so that you can better appreciate the importance of our commitment to continuing to meet these specialized data needs.

The Organization of Health Statistics Systems in the Department

PUBLIC HEALTH SERVICE

As you know the Public Health Service is the principal health agency of the Federal Government. Its mission, in its broadest and simplest terms, is to protect and advance the health of the American people. Health data activities of the Public Health Service, support this mission.

The Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) has responsibility for national research, training and services in the areas of alcoholism, drug abuse and mental illness. Its three component agencies, the National Institute of Mental Health (NIMH), the National Institute on Alcohol Abuse and Alcoholism (NIAAA) andthe National Institute on Drug Abuse (NIDA), each engage in a number of significant statistical activities directed at identifying the location and characteristics of facilities, programs and personnel providing services to their target population; counting the numbers and characteristics of persons served by their program funds; determining charges and sources of payment for services; and assessing the effectiveness of services provided.

The Centers for Disease Control (CDC) is the Federal Government's focal point for the prevention and control of preventable diseases, laboratory improvement, epidemiology and surveillance, health education and occupational safety and health. CDC's overall mission is to monitor disease patterns and to provide assistance to State, local and other health related institutions in controlling disease and preventing its reoccurrence. As the incidence of known communicable disease has declined, CDC's programs have been expanded to include noncommunicable but preventable diseases in areas such as environmental health, toxic waste and dental diseases. Data are collected from State and Local health departments and published weekly on the occurence of immunizable diseases and other infectious diseases including hepatitis, botulism, tuberculosis, venereal diseases, pneumonia and influenza.

The Food and Drug Administration (FDA) is a regulatory agency whose primary mission is consumer protection in certain areas of health.FDA plays a significant role in influencing the Nation's health status and in assuring the effectiveness of the Nation's health care delivery system by ensuring that: (1) food is safe and wholesome, (2) drugs, biological products, therapeutic devices, and diagnostic products are safe and effective, (3) cosmetics are safe, (4) the use of radiological products does not result in unnecessary exposure to radiation, and (5) all of these products are honestly labelled. In addition, FDA engages in special studies and data collection dealing with nutrition education and knowledge, food additives usage, perceptions concerning product labelling and patient-packet inserts, adverse reactions to drugs cosmetics, and prescription drug advertising.

The Health Resources Administration (HRA) is responsible for identifying health care resource problems and maintaining or strengthening the distribution, supply, use, quality and cost-effectiveness of these resources in order to improve the health care systems and the health status of individual members of the population. In order to carry out its mission effectively, HRA requires extensive data on health care resources.

The Health Services Administration (HSA) has responsibility for those programs of the PHS that deal with direct service delivery to statutory beneficiaries, building the primary care capacity for medically underserved populations and for assuring quality in Federally financed health care services. The Bureau of Medicalservices operates several data systems to provide planning and management information both for PHS hospitals and outpatient clinics. The Indian Health Service data systems supply information on services provided IHS hospitals, clinics, laboratories and by community, social, and mental health workers. Through a management data system called the Bureau of Common Reporting Requirements, the Bureau of Community Health Services collects uniform program data from all health service delivery projects funded. Data is collected on patient characteristics, service utilization, staffing and costs.

The National Institutes of Health (NIH) is the lead Federal agency for biomedical research concerning the prevention, diagnosis, and treatment of disease. The management of such an enterprise involves decision making requiring a wide variety of data. One type of data focuses on the incidence, prevalence, and cost of disease in the country required for the establishment of research priorities.

Another type is epidemiological data which provide non-laboratory statistics for testing hypotheses relating to disease states and conditions and are important in complementing the search for the etiology and pathogenesis of diseases. A concerted effort is underway in NIH to review and identify common needs for data of this sort in the various Institutes and Offices of the NIH in order to ensure that the limited funds for such statistical andanalytical activities are used in the most efficient and effective manner. In addition, the National Library of Medicine of NIH maintains information systems such as MEDLARS, the Chemical Data Base Directory and Toxicology Data Bank and provides a number of on-line health information services to hospitals, such as Chemline, Toxline, Medline and Cancerline.

The Office of Health Research, Statistics and Technology (OHRST) is the principal office within the Office of the Assistant Secretary for Health concerned with health statistics. OHRST includes the National Center for Health Care Technology, the National Center for Health Services Research, and the National Center for Health Statistics, one of the five major general purpose statistical agencies of the Federal Government. OHRST not only strengthens the Department's capability to stimulate and assess technological developments in health and apply the latest technologies to medical practice, but strengthens the relationship among technology assessment, health services research, and health statistics as a basis for health policy formulation.

THE HEALTH CARE FINANCING ADMINISTRATION (HCFA)

As the agency responsible for the Federal Government's two major health care financing programs -- Medicare and Medicaid, HCFA maintains large data files describing Federal health care expenditures, health care providers, and HCFA program beneficiaries. Information is essential to the Health Care Financing Administration. Data collection, *per se*, is not primarily for statistical or research purposes. Statistical and research needs are met as a by-product of the data collected to administer the program.

Medicare program statistics are maintained centrally on a person level. Linkages are made across beneficiary, claims and provider information. Medicaid program statistics at the Federal level are aggregate and do not allow for person-based linkages and analyses. The majority of these data are produced as a direct result of bill processing and related support systems established to reimburse providers of health care services under Medicare and Medicaid.

HCFA's health data requirements can be divided into four general categories:

- data related to provider reimbursement systems, including information on the nature and costs of health care services received by HCFA program beneficiaries;

- data related to HCFA's quality assurance programs, which are required for the monitoring of quality characteristics of health care providers and which includes data to support peer review under the Professional Standards Review Program in the form of provider profiles and "norms" of health care;

- data related to program and project evaluation, including empirical evaluation studies of the impact of major programs and demonstration projects on an ongoing basis; and

- data related to research and initiatives in the area of cost containment and health care reimbursement reform.

HCFA is supporting several activities related to the establishment of standards of communication among users of patient utilization information. These include:

- The establishment of minimum data sets for billing and discharge information that will be generated by each provider for each patient.

- The concurrent establishment of well-defined, mutually exclusive, standard codes to be used in recording certain patient utilization information elements.

- The establishment of standard formats for recording and communicating patient utilization information.
- The funding of "integrated data demonstrations" in several States to consolidate and integrate the transfer of hospital claims and discharge information within a State.

While HCFA and the PHS agencies must maintain specific individual data systems, it is possible to expand through integration and coordination the benefits that accrue to the potential users of these systems. In my view, this is the direction in which the Department should and will be heading. With this thought in mind, I would like to provide several examples of integration and coordination which lead to this expandsed usefulness.

Examples of Integrated Systems

An excellent example of intra and inter-department coordination is the Health and Nutrition Examination Study (HANES) conducted by the National Center for Health Statistics. The mission of HANES is the collection and utilization of data which can be obtained only by direct physical examination, clinical and laboratory tests, and related measurement procedures.

The level of collaboration involved in HANES II has been exceptional:

- The Center for Environmental Health, Centers for Disease Control (CDC), has continued to serve as a technical consultant for the planning and quality control of HANES laboratory efforts in addition to performing most of the health and nutrition related biochemistries and providing some of the funding for this effort.

- The National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases, National Institutes of Health (NIH), has supported the serum creatinine determination, the development of a glucose tolerance testing protocol, the plasma glucose determinations at the CDC and the processing of the data to make it more quickly available for analysis.

- The National Heart, Lung, and Blood Institute, NIH, developed plans for assessing cholesterol, triglycerides, and high density lipoprotein (HDL) levels through the Lipid Research Clinic Laboratory at the George Washington University, and processing the results at the Coronary Patient Registry at the University of North Carolina.

- The Office of Pesticides and Toxic Substances, Environmental Protection Agency, has served as a technical consultant in collecting blood and urine specimens suitable for processing for residues and metabolites of certain pesticides; has processed the samples and monitored the quality of the processing; and has coded the data in machine readable form.

- The Bureau of Foods, Food and Drug Administration, supported the development of a serum ferritin assessment as part of characterization of anemia and supported the measurement of blood lead levels at CDC.

- The Department of Energy supported research at the University of Pittsburgh concerning the assessment of carboxyhemoglobin levels in blood. The Naval Medical Research Institute served as final arbiter in the assessment of carboxyhemoglobin levels in blood.

Another promising example of integrating data systems is the use of Clinical Data Banks. Clinical Data Banks represent a new approach to the assessment of clinical decision-making and the evaluation of specific diagnostic and therapeutic technologies. They are, in my opinion, a current test of a coordinated approach to data systems in that they provide immediate clinical and health care delivery related information. The NIH and NCHSR have pioneered development of and provided funding for Clinical Data Banks. These types of systems enable us to link together sources of information on selected health problems -- problems to which we have committed major resources. It is anticipated that this networking of Clinical Data Banks could provide answers to some of our pressing health care problems.

At Stanford University, a Clinical Data Bank is developing and evaluating a computer-based system for alerting on potential drug reactions. Prescription data is cross-checked with stored information about other drugs used by the patient. The Computer program (MEDIPHOR) alerts for possible adverse reactions.

At Massachusetts General Hospital, a study to develop a modular hospital information system and computer-based ambulatory medical record system has produced pioneering research in the use of shared computer systems for medical purposes and the development of a computer language designed for health care needs.

The Health Care Financing Administration is examining alternative approaches to collecting and processing patient utilization data. One alternative, called Integrated Data Demonstration (IDD) Systems, is being tested in several forms in conjunction with a number of state organizations.

A common objective for each IDD is to involve all significant users of patient utilization data information in the definition of common data sets. A goal of the IDD's is one time collection of patient utilization information to meet the needs of these multiple users. Over the last few years, HCFA has made grant awards to develop IDD systems in nine states: Iowa, Maine, Minnesota, Missouri, New York, South Carolina, Vermont, Massachusetts and New Hampshire. New York received the first IDD grant in 1977 and has succeeded in implementing its system statewide. As a result, the New York State legislature has recently appropriated $3.7 million and assumed responsibility for the funding of the IDD from the Federal Government.

Conclusion

Mr Chairman, I have outlined some of the issues and formidable problems confronting the development and implementation of a coordinated health information system. In addition, I have attempted to highlight the Department's current efforts in the area of data coordination.

I believe that the key issue before the Committee today -- how to make the best use of the data we as a Nation collect -- is an important and challenging one. I also believe that the ongoing demonstration projects and efforts of the Department of Health and Human Services in this area can provide some insights into new directions in which to move to better meet this challenge. As one who shares your concern and commitment to this issue, I would like to offer the Department's assistance as you continue your consideration.

I believe that great progress has been made since the last time I appeared before this Committee and I am confident that more can and will be accomplished in the years ahead.

Thank you, I would be happy to respond to any questions Members of the Subcommittees may have.

Mr. SCHEUER. Well, we appreciate your coming very much. We are sorry we had what I presume is a misunderstanding, but nevertheless you are here and we have benefited from your testimony.

I will not ask you any questions at this time. But I, frankly, would like to review your testimony.

You have departed in some respects—or elaborated in some respects on your prepared testimony, and I'm inclined to do a more detailed, orderly job when we can arrange for it to be convenient to you to come back.

Mr. BROWN. Just let me ask a couple of policy questions, Dr. Brandt.

In view of your preliminary remarks about the difficulty in establishing a comprehensive system with regard to uncertainty of costs and benefits and quality, and issues of control, and so forth, will it be your intention to recommend to the Department any reduction in effort at getting the States, as in the case of New York, concerning your testimony to continue, decrease, or increase what they are doing in terms of developing relatively comprehensive systems?

Dr. BRANDT. Well, it will be our intention to encourage the States to continue and to expand and enhance their development. You should be aware that the States have gotten together, in fact, and do sponsor a reporting system for chronic and other diseases treated within their borders that we operate for them under contract. That system, because of budgetary cuts, has been somewhat impeded, but we have managed to transfer a little money around here and there and keep that alive for the foreseeable future. So we are working very closely with States that wish to develop such systems and will continue to do so.

Mr. BROWN. On page 12 of your testimony, you made reference to the Paperwork Reduction Act, which was enacted last year. This was an effort at developing congressional measures toward the better planning and integration of complex information gathering networks.

I think, if I recall, you stated this has had a bad effect on the momentum of the Department in this regard. Can you indicate whether or not the Department has implemented the pertinent requirements of the act? I have in mind the things you referred to—the locator system directory, data element dictionary you have, more specifically the designation of a high-level policy official to be responsible for coordinating information and work within the Department.

Dr. **Brandt**. Well, clearly, we have not completely implemented the act in the last 6 months or so, but we are, in fact, taking steps toward all of these efforts. I am afraid, unfortunately, I can't tell you right this moment. Ms. Hanft is, in fact, the senior official. She is my Deputy for Health Research, Statistics and Technology, and she is the responsible person.

I did mention the internal committee which is reviewing all of the policy toward this end. And we are, in fact, implementing this act, step by step, in a reasonable way.

Ms. **Hanft**. We are working directly with the Office of Management and Budget on the Federal locator system. We are now completing our second development of an information budget, and the Health Data Advisory Committee will be reviewing that budget.

The Public Health Service was a little in advance of that legislation. We have developed some standardized information and data sets, which have now been adopted throughout the Public Health Service, and definitions are soon to be adopted. The Health Data Advisory Committee has just approved them throughout all the Department systems. These are initial steps toward implementation of the act.

Mr. **Brown**. Well, I am please to hear that and to note your remarks with regard to the potential that the act has with regard to developing a coordinated Federal health information system.

Mr. Sensenbrenner, do you have any questions?

Mr. **Sensenbrenner**. No questions, Mr. Chairman.

Mr. **Brown**. All right. I will defer any further questions I have, also, until we have an opportunity to further review the testimony.

And let me repeat Mr. Scheuer's expression of appreciation to you, Dr. Brandt, and apologize for any misunderstanding.

Dr. **Brandt**. Thank you very much.

Mr. **Brown**. The subcommittee will be adjourned.

[Whereupon, at 12:05 p.m., the subcommittee was adjourned.]

HEALTH INFORMATION SYSTEMS

THURSDAY, JULY 23, 1981

House of Representatives, Committee on Science and Technology, Subcommittee on Science, Research and Technology; Subcommittee on Natural Resources, Agriculture Research and Environment,
Washington, D.C.

The subcommittees met, pursuant to call, in room 2325, Rayburn House Office Building, Hon. James H. Scheuer (chairman of the subcommittee on Natural Resources, Agriculture Research and Environment) presiding.

Members Present: Representatives Scheuer, Walgren, Brown, Shamansky, Carney, Sensenbrenner, Skeen, and Gregg.

Mr. **Walgren**. The committee will come to order. We expect Mr. Scheuer to be here momentarily, but in his absence, we will start.

Welcome, Dr. Brandt, on your return to the committee.

It is my understanding that you do not have another formal statement to give at this time but you are here to respond to the committee's interests?

Dr. **Brandt**. That is correct.

Mr. **Walgren**. Is there anything you would like to say at the outset. Then I would like to recognize Mr. Brown to lead off.

Dr. **Brandt**. Yes, sir, there are a few points I might make, Mr. Chairman.

As you pointed out, I am here to respond to questions after giving formal testimony on June 4. At that time, I submitted a rather lengthy statement for the record concerning the Department's attitudes and views about the comprehensive health information system.

In response to the letter, Mr. Chairman, which you and Mr. Scheuer sent, I would like to point out that I also share your concerns and those of this committee for the need to improve the health data systems of this country in an attempt to help us better identify disease and disability.

Not only am I interested in this in my official capacity, but I spent my entire professional career as a physician concerned with biostatistics and computer science. I have run a medical computer center in the past and am familiar with the problems of health information.

I think the basic point that I was trying to make in that testimony is not that I doubt that a comprehensive health information system might someday be developed, but that to think about doing that today anticipates a more ideal state of knowledge of medical sciences and health data than we currently have.

Therefore, my plea was for us to be realistic and pragmatic as we approach our vision of a comprehensive health information system. That does not mean that we should not begin to develop some incremental steps in that direction, but I think they should be very carefully and cautiously done.

In large part, in response to this committee's interest in the issues, I have begun an examination of the way in which the Department currently determines health data needs and coordinates its health statistics activities.

We have a Health Data Advisory Committee, which advises the Secretary on health data-related issues. We are taking steps at the present time to improve this committee's effectiveness, to make it an effective, working body, and begin to develop some of the incremental steps.

Finally, I think that it is important to ask the question: What is this comprehensive health information system? what needs is it intended to fulfill, or to meet?

We have to recognize that medicine, particularly clinical medicine, the care of individual patients, and indeed epidemiology and public health are still as much an art as they are a science. It is just not possible to quantify human distress in meaningful ways. It is not possible for us to always find the answer to public health problems before the need to move in and do something about them—witness Legionnaire's disease, toxic shock syndrome, other sorts of things—and it is sometimes necessary for us to use judgment and insight.

None of these can be built into a system and it is possible for such a system to interfere with such judgment. Therefore, again I would recommend that we honestly examine all of the uncertainties that face us as we begin to move in that direction.

I think that sort of summarizes what I would like to say in response to the letter which you sent. I am in agreement that we need to take a look at this, but I am concerned that we do it cautiously and carefully and not anticipate or have expectations which are not based upon real pragmatic concerns.

Mr. **Walgren**. Thank you very much.

The Chair recognizes Mr. Brown.

Mr. **Brown**. Dr. Brandt, let me first thank you for your response to what I am sure must appear to be a little bit of harassment by these two subcommittees. I assure you that harassment is not intentional. We have some of the same frustrations that I am sure you encounter. I have been impressed by your effort to seek a constructive outcome from our interchange here, and I want you to know that I do appreciate it.

We can sometimes be unrealistic, based upon our lack of detailed knowledge of what is possible or realistically possible. On the other hand, we sometimes think of ourselves as having some vision of what the country needs and we wonder why we cannot get to it a little faster and out of this exchange or interchange, we hope that there will be some reasonable progress toward utilizing all of our resources for more effective service to the people of this Nation, and I think, I trust that you feel that there is some hope that we can do that also.

In the interim of the last few weeks since we talked last, I have taken it upon myself to visit two of the hospitals which have outstanding systems, the Bethesda Hospital, and the one out in California at Mountain View, El Camino, which was one of the pioneering systems. I have been very much impressed, without pretending to understand all of the ramifications of the system.

I saw some things there that I felt had a great deal of promise for the improvement of medical practice, and I understand that there are a substantial number of such hospitals that have reasonably comprehensive systems, possibly a couple of dozen or more around the country.

Dr. **Brandt**. I think that there are probably between 20 and 30 hospitals with pretty comprehensive systems, yes.

Mr. **Brown**. What we would like to envision is the possibilities that this development could proceed as it obviously is, and proceed on the basis of some comprehension, some definition possibly of what the national potential is for a system that was in some way reasonably well integrated to serve the national needs.

Now, I have no idea of how you would go about putting together an integrated system, and I think it will take quite a bit of effort by more knowledgeable people than me to do that, but what I am concerned about is whether or not there are any institutional provisions.

We tend to look on you as the Federal Government's chief health officer, to give us some assistance in envisioning the kind of future that exists here, without necessarily forcing you into something that is impractical and unrealistic.

I am encouraged by the fact that you feel it may be possible to do more and that you have an apparatus in the Health Data Advisory Committee that might provide some mechanism there.

Could you indicate to us how you feel the committee can be of service to you and the kind of contribution it might make in helping to visualize some sort of national scheme? And I am not talking about a federally directed comprehensive system, but I am talking about a conceptual framework within which we might help to guide the development of this important area.

Dr. **Brandt**. The most important aspect of attempting to have an integrated system that is in fact comprehensive in scope had to do with data definition.

The Health Data Advisory Committee is going to be concerned with two things. One is to come up with some standardized definitions that we will not only use within the Federal Government, but also attempt to work with the professions and the other groups in the private sector in an attempt to get them accepted, so that we can begin to build upon this at least common base.

The second is to deal with the issue of so-called minimum data sets, to attempt to determine what is, or what are the minimum measurements or minimum amount of definitions required for disease entities.

The Department and the Public Health Service have a number of activities underway, in addition to that committee, that I think are the kinds of incremental steps that I was talking about. For instance, the comprehensive system at the NIH Clinical Center is in fact not only a working model for clinical management, but it allows us to run a number of experiments to test various approaches, to look at deficiencies and problems encountered in the management of large amount of data from patients, and its involvment in clinical decisionmaking. So I think that in itself it is providing us with a lot of understanding.

Second, through the National Center for Health Services Research, we are funding a number of research projects around the country also concerned with those same problems that again allow us to gain the kind of information that will be necessary for decisions to move toward a comprehensive health information system.

Finally, the Centers for Disease Control, which runs a monitoring system for a number of diseases, as well as for a number of operative and other procedures around the country, is now experimenting with the receipt of these reports and other information from State health departments and other official health agencies, computer to computer, so that we can in fact be responsive, alert, and help State health departments in the growing potential in epidemics and so forth.

We are moving on the clinical side to hospital information systems approaches, on the public health side via the CDC, and I think the Health Data Advisory Committee can now sit down and begin to deal with the really fundamental, basic problems of data definition and minimum data sets so we can begin to talk about integrating.

Mr. **Brown**. Obviously, these are important building blocks in creating a system and deserve the attention which the committee can give to them. I hope at the same time, they can be following a path of trying to envision the broader benefits of a system that would provide some opportunities that we are thinking about.

Let me mention a couple of things that disturb me and ask you to comment on them.

We have heard in the last 2 or 3 days, in another subcommittee, testimony with regard to the contamination of ground water supplies by minute amounts of toxic chemicals, in some cases pesticides. One witness testified to the application of a particular pesticide on Long Island to the potato farms there. It turns out it got into the ground waters and made it impossible to use the wells which were the supply for several of the towns on Long Island.

Those wells were shut down by State authority, and in some cases, it produced a tremendous economic hardship on the cities which had to import water for domestic use for the township by tank truck, which is an impossible cost for a township.

The problem is that because the testing of the wells was fairly recent the health effects nature of the chemical was not precisely defined. There was no history of how long people might have been drinking some of this contaminant. It is a classic situation where there is a need for epidemological studies on a long-term basis and yet, there are no studies being done.

It seems to me this is a made-to-order situation for a large scale integrated medical information system or health data system, whatever you want to call it, that would provide us with the epidemiological tools necessary to trace the impact on the health of a substantial population on Long Island over a considerable period of time, and yet we do not seem to have the resources or the mechanisms to accomplish this.

It seems that this is one of the benefits that might come about from a more comprehensive system of health data. Am I being unrealistic in envisioning this as one of the possible applications of a system of this sort?

Dr. **Brandt**. I think ultimately what you are describing is conceivable in that kind of a system, particularly with respect to monitoring the population over a long period of time after known exposure.

One of the problems that a country faces, and one of the reasons that it is difficult to get epidemiology studies done is that there is a marked shortage of competent epidemiologists in this country. We are attempting to alleviate this. We have a Public Health Service-wide epidemology training program now in an attempt to get around this, but the kind of situation that you are describing is going to become more common.

I think it is necessary for us to set up the mechanism to follow people, because unfortunately, the exposure to toxic chemicals often does not lead to an acute problem, but it may lead to a long-term problem that we are totally unaware of at the present time. We have to begin to explore these in a much more systematic fashion. Certainly it is possible that a comprehensive system would in fact be of great value in that effort.

Mr. **Brown**. Given the other aspect, the shortage of epidemiologists and the money it would cost to fund the program?

Dr. **Brandt**. Yes, the problem with toxic substance exposure is precisely what you are talking about. The fundamental problem really is knowing the exposure of any particular individual because you don't know for sure when the material gets into the water, how much water they have drunk that was in fact containing the material and that sort of thing. So those problems get complicated very quickly if you don't know the exposure.

Mr. **Brown**. We have another technological revolution that contributes to this and that is the development of very sophisticated monitoring measuring systems which allow us to detect quantities that previously we were unaware of. But we need to be prepared to move on the basis of new information in one area with new approaches to that information in other areas. This is the kind of thing that we seem to be in short supply of.

Let me make one additional point in the form of a question before I yield to my colleagues.

The question is in connection with the visit that I made to the facility at Bethesda, where they have spent a number of years, I think it is 7 or 8 years developing their system. They probably have accumulated the preeminent store of information as to the kinds of problems involved in deploying the system and so forth. They indicated, or it was indicated there—and I don't want to identify individuals—that they had been visited by staff from the Veterans' Administration, from the DOD, and from other agencies which were considering the installation of computerized systems of a similar nature, or parallel to it. They had given them the same sort of a tour that they gave to me, which is not necessarily all that fancy, but there had actually been a minimum amount of coordinated planning on the part of any other Federal agencies to benefit from the experience and mistakes that had been made.

I would consider that a deplorable situation if it actually exists. A substantial amount of money and trained manpower having gone into developing and debugging that system, and it appears that, if I understand correctly, and I may not, that there is a minimum amount of effort by other parts of the Government to utilize all of the accumulated knowledge and experienced developed there.

I don't know whether you personally are familiar with that situation or not. I would ask you to comment as to whether you think that is the best way to run a railroad, and if it is possible for you to do anything about it if the situation is as I seem to perceive it to be?

Dr. BRANDT. Obviously I think the NIH has demonstrated that they have a system that is working. It is working in a very selective environment, because they control completely the types of patients that are admitted to that installation. All of these patients that are admitted are on some kind of research protocol which again puts you into a somewhat different circumstance than either the Department of Defense or the VA.

I have not discussed this with either one of those agencies, but I can assure you that I shall see what the problem is with making use of it.

Mr. BROWN. Thank you, Dr. Brandt.

I will defer to my colleague.

Mr. WALGREN. Thank you, Mr. Brown.

The Chair will recognize Mr. Carney.

Mr. CARNEY. Thank you very much, Mr. Chairman. Dr. Brandt, I thank you for coming back, too. Unfortunately, I was on another committee hearing out of the country on a factfinding mission when you were here last and not able to be part of the hearing that we had.

I have some questions of concern. One is related to the utilization of the information and the other concerns the protection of people's privacy. Now, we have an experimental program going on over at the NIH. Have they been looking into those two questions? Mr. Brown was touching on it, he felt we were not utilizing the system that now exists within the Government.

My question is this, will the health community utilize the system if we gave you the best you could have?

Dr. BRANDT. I think, without much question, that the medical community will use the information system which provides the kind of information that they need for decisionmaking and proper care. I think the fact that we have between 20 and 30 hospitals in the country that are now using such systems, including NIH, which in my judgment has probably the best system, tells us a lot. But NIH is a special situation; its system is a controlled environment, and all the other things I mentioned a few moments ago.

I don't think there is much question that such a system will be used. However, I think it is also important to recognize that these systems are still highly dependent upon the quality and definition of data that goes in them. I know of no two such systems, for example, which could at the present time be totally integrated and give meaningful information to a physician, because the definitions are not the same, and the way in which the data is collected is not the same, the quality control is not the same.

Now, there are experiments going on and demonstrations going on, most notably probably being at Duke University in cardiology, but they are all limited to specified areas. We are learning from those, and we will benefit from them as we move toward this kind of activity.

With respect to the problem of privacy——

Mr. CARNEY. If I could interrupt you at that point.

You were mentioning the problem of definitions. I believe in our testimony you said that it was a problem in reverse. You were afraid it might stifle initiative, it might stifle people from researching new diseases if you did that. Are you going to have a problem with definition on both sides?

Dr. BRANDT. I am not talking about definition being the stifling factor, say that, for example, diabetes were to be characterized by the following and that is it; that we are going to fail to recognize new manifestations of diabetes that may come in and because technology has improved so much in medicine, we now recognize many manifestations and consequences of diseases that have been known for a long time. We want to be sure, first, that we don't suddenly lock ourselves into, say, that this is diabetes, and this is the way it will always be, and we will never learn anything more about it. And that is the problem with a rigid system.

In the early days of computing, when I first got into it and started working on information systems—about 1968—we made that mistake repeatedly by just saying this is it and this is as far as we are going, and then people would come in with new observations and we would tell them that we are sorry, that they just didn't have it right, or they had made a mistake someplace along the line.

We are smart enough not to do that this time around.

Mr. CARNEY. I see. You do have it from the two perspectives.

Dr. BRANDT. That is correct.

Mr. CARNEY. When you hit definition, it appears to be the key to a lot of your testimony.

On the privacy question?

Dr. BRANDT. The privacy issue is one of the most difficult problems we have to deal with. Although I believe that individuals are entitled to privacy in all of their matters, I suspect that one of the major areas, and one of the most important areas is their medical record, and particularly their medical history.

I don't think it is necessary for the entire medical record to be available to treat any kind of illness that a patient comes in with. There are some things that are of value in treating certain kinds of illnesses, but if you are treating someone for a common cold or sore throat, I do not think that one needs to have all of the background information that may not be germane to that problem.

Therefore, I would be concerned, even though we can build various kinds of safeguards, about the kind of comprehensive health information system where you would have all of that information available to anybody. It might be possible for an awful lot of people to have access to the total record who really didn't need to know that total picture. That in my opinion is a solvable problem but it is not solved at the present time and we will have to work toward its solution.

Mr. **Carney**. The method of solving that problem would primarily involve being selective with the input?

Dr. **Brandt**. One could be selective with the input, that is one approach. One can also be selective at what you can get out of the system. For example, in some of the systems currently operating, there is a kind of hierarchy of access to information. That is, certain information is available, let's say only to the patient's primary physician. Certain other information is available to the consultant physician. Certain other information is available to the floor nurses.

That is the kind of hierarchy one can build into such a system. Again, we are talking about a very limited kind of system, not a total, comprehensive system. Those systems that are in operation today certainly are not as comprehensive as what we are talking about at these hearings, so it is a problem that is solvable in my judgment, but it won't be solved unles we pay attention to it.

Mr. **Carney**. As with all computers, what you get out is only as good as what you put in. Everybody has a story about that, just yesterday I got a letter from a constituent having a problem getting a VA mortgage. When he made an inquiry, the VA wrote him back informing him he had died.

Dr. **Brandt**. That must have come as a surprise.

Mr. **Carney**. They told him sorry, your records indicate you are dead. Have you ever had a similar problem?

Dr. **Brandt**. Yes.

Mr. **Carney**. I suspect you can only approach it as you go along. There is no way you can design a package from a single patient. It is a learning process that progresses as you continue to utilize new technology.

Dr. **Brandt**. Yes, and I think that we are moving along that pathway right now. I believe that we have got to take it one step at a time. And you are right, we are learning a lot and we will continue to learn a great deal and be able to get better at it, and thereby be of great value to the people, which is really what we are talking about.

Mr. **Carney**. Doctor, I thank you again for coming back.

Mr. Chairman, that is all the questions I have.

Mr. **Scheuer**. Thank you.

Congressman Gregg.

Mr. **Gregg**. Thank you, Mr. Chairman.

I have two questions. I get the feeling you are not that enthusiastic about proceeding along the lines of having a system?

Dr. **Brandt**. I am enthusiastic about proceeding toward the development of that system slowly and deliberately and realistically. That is my only concern.

I think we have to begin now to design a system—using design in the sense of thinking about a system that goes beyond our current collective ability. There is an old saying about computing, that the person who projects 5 years in the future will be too optimistic, and the person who predicts 10 will be too pessimistic, because that is the rate at which technology is advancing. I think we have to begin to lay something out for the future. I just don't think we can do it all right now.

Mr. **Gregg**. The Department of Defense testified at a prior hearing, and they seem to be fairly far down the road in this area. They are talking about creating various hospital systems within their own defense organization, both the Air Force, Navy and Army.

Have you taken a look at their systems?

Dr. **Brandt**. They have a closed system, Congressman. They control the people that are in there, in the sense that they have got ID numbers. They go to a limited number of hospitals under a limited number of circumstances. They can make up their own definitions and deal with those internally, so that there is a system. It is still not like trying to get for example, George Washington University Hospital and Northwestern University Hospital, to come up with a standard data set or even a standard numbering system for identification of patients.

Mr. **Gregg**. They seem to feel that in 3 or 4 years their system might be available, when we asked whether or not it would be available to the private sector. You don't think that is realistic?

Dr. **Brandt**. I think that that is awfully soon.

Mr. **Gregg**. Do you anticipate that the private sector would be able to evolve a system like this without the support of your agencies?

Dr. **Brandt**. Without the financial support?

Mr. **Gregg**. Financial and just the backup, the techical information which you have?

Dr. **Brandt**. No question, the technical information and so forth is readily available, and we would share it with them. Clearly, it is all in the public domain, so that would be no problem.

In my opinion, the private sector right now is probably better able to develop these sorts of things, than is the Government as such. It probably would result in some kind of a partnership with us sharing the accumulated information, because we have been supportive of research and demonstrations and other activities for a long time and have accumulated a great deal of information, most of which is available.

If you look at the working systems, with the exception of the NIH system, most of them have been developed in the private sector, although we have supplied some of the basic funding early on.

Mr. **Gregg**. Thank you.

Mr. **Scheuer**. Congressman Joe Skeen.

Mr. **Skeen**. No questions, Mr. Chairman.

Mr. **Scheuer**. Dr. Brandt, you probably have some sense that there is a little frustration here. In your testimony you have adequately identified the problems of moving toward a comprehensive health information system but did not seem challenged by the opportunities and the enormous potential of such a move. You are now telling us that we shouldn't really be moving toward a comprehensive health information service, or if we do, we should do it slowly, deliberately, and really particularly.

I get the sense you don't feel there is anything in the technology that would justify a major effort to apply the highest and best state of the art of computer sciences and the product of the information revolution that is hitting almost every other area of American life, and impacting almost every area of American life other than health services. So far we have not made a major impact on getting a hold on health costs: The costs of a particular operation, surgical procedure, or the cost of care per patient, either among hospitals in one area or between hospitals in the East and hospitals in the West, or hospitals here or abroad.

We really do not have the data to evaluate the cost effectiveness of what we are doing, nor have we equipped our doctors with computer assisted diagnosis and treatment that would radically enhance the quality of patient care.

Can you see no systematic way in which we could move in a reasonably brief period of time in both improving the quality of patient care by giving computer assistance to patients both in diagnosis and treatment, as well as improving the quality of taxpayer's pocketbook by moving in a systematic way toward getting a handle on health care costs?

We are already spending well over $200 billion a year on health care, a far higher percentage of our GNP than any other country in the world, and if you look at some of the indexes of health outputs, they are not something we can be terribly proud of. We are approximately 15th in the world in infant mortality, as I recall.

We should be producing a lot more in terms of health outputs for our health dollar expenditure, and in the past we have not been able to get a handle on it. We in Congress feel as if we are trying to punch our way out of a wet kleenex. The system is too big, too gelatinous. The human mind cannot comprehend this system and get a handle on it and systematize it. There are too many variables, and many of us here feel frustrated and have been frustrated long before you arrived on the scene in your present position. The frustration is not at all directed at you but over several administrations. We feel that they have missed the boat and have not really addressed themselves in a serious systematic way toward applying the knowledge of the information revolution, while we have learned that it is so radically affecting other aspects of American life that it should be applied to the business of improving health quality and health care cost effectiveness.

We are really suffering an acccumulation of frustrations and you happen to be the unhappy victim because you appear here this year in this position of critical responsibility. I do want to make it perfectly clear that this is not directed at you the person, but it is directed at you the institution—nameless—and this has been an accumulative process of a feeling of hopelessness that there would be breathtaking breakthroughs in the improvement of health care and our ability to improve health costs, if only we were able to put the pieces of the jigsaw puzzle together.

We don't get the feeling we ought to design a system that is inflexible. After all, the computer is basically a system for storing information, and that information input and that information retrieval can be designed in any way that human beings care to design it. The computer is able to store tens of billions of bits of information, and is able to regurgitate that information in any way that we choose to command it.

There is nothing about a comprehensive health information system that is intrinsically inflexible, unless we design it that way. What we have at our disposal is a system that can absorb and file 10, 20, 30 billions of pieces of information and relate them in ways that we instruct that computer to relate them.

The human being is in charge, and there are no constrictions on inflexibility the fault of which wouldn't lie at our doorstep. That is the way it ends up.

What we are trying to get from you is the feeling of hope that serious minds will be applied to this business of taking the computer that is so radically impacting other areas of American life, and sophisticated information systems of all kinds, and applying them to health care.

In the weeks that have passed since you last appeared here—and we are very grateful to you for your patience and tolerance in coming back here now, and we thank you for that—have you had any reflections that you could pass on to us that would make us feel better?

Dr. BRANDT. I did not intend to convey hopelessness or to try to say there was no hope in attempting to approach a comprehensive health information system. I think there are a lot of ways at the present time in which computers are being used and in the fashion that you were talking about.

For example, there are very few coronary care units where the patients are not being monitored, and where it isn't possible to do some early warning of potential complications of patients. That, it seems to me, is a significant use of machines, and in all intensive care activities, of course, now to monitor patients from long distance is becoming routine. But I will assure you that one of the dilemmas that we face is that those activities have not in any way reduced the cost of health care. They have in fact increased it. They have saved a great number of lives and I think, the quality of life for a lot of people. And therein lies a dilemma I know you have to face, and all of us have to face, and that is the tradeoff between the two.

Certainly the National Library of Medicine is now the worldwide leader in the dissemination of information, the availability of information. It is now possible for physicians almost anywhere in the world, certainly anywhere in the United States, to have access to the information in the world's literature both through MEDLINE, and through a number of specialized services.

We were talking earlier about toxic wastes. The TOXLINE is the most complete source of information about the effects of toxic substances that the world has ever known. It is available right now and operational and moving, and available again to every physician and other people throughout this country. So I think there are a lot of pieces that are coming together, and all I have been trying to say is "yes, we are going to pay attention to it."

We are going to move in that direction, but I am not sure that we are at the stage now where I could tell you and give you a chart that says this is what we are going to accomplish on a 6-month or yearly basis. Perhaps if things go well, by the time I leave, I might be able to do that, assuming that there was enough time to accomplish it.

Mr. **Scheuer**. Can you tell us what mechanisms have been established to coordinate the data collection, within all of the Government agencies dealing with health, to monitor the effectiveness of our health policies?

Dr. **Brandt**. There are no mechanisms that monitor from all agencies within the Federal Government. We have within the Department of Health and Human Services a statisical policy group, which in fact monitors all of the information that we collect on health matters, and all of the data that we collect, and that sets forth the policies under which it will be collected.

Mr. **Scheuer**. And would that include the Veterans' Administration?

Dr. **Brandt**. No sir; it does not include any agencies outside of the Department of Health and Human Services, except as they voluntarily make use of it.

Mr. **Scheuer**. Assuming you had the legislative authority to do it, do you think it would be useful to have one centralized computer based source of health problems and health effects flowing from all of our agencies that either do research or deliver health services?

Dr. **Brandt**. I think it would be useful, as long as we permitted those agencies to collect information that was of value—I mean, uniquely of value to them.

For example, the VA's information, which would pertain to determinations of disability and other things, I would think that they would want to continue to collect because they need it to carry out their function above and beyond the health aspects of their system.

Mr. **Scheuer**. The National Commitee for Vital and Health Statistics and the NCHS have developed several minimum data sets. Has your department accepted these, and are they being implemented?

Dr. **Brandt**. Some of them have been accepted. Some are being implemented. Not all have been accepted yet. Only one has now been implemented.

Mr. **Scheuer**. What is the status of the others?

Dr. **Brandt**. The others are being tested. One of the situations we are concerned about is their acceptance by the profession generally.

Mr. **Scheuer**. Yes, well, isn't that a question of leadership in the department? Isn't that a question of leading the profession into new and better, more effective ways of functioning both in terms of quality and costs?

Dr. **Brandt**. Yes, I think it is.

Mr. **Scheuer**. It seems to me from my knowledge of you, and my observation of your testimony, and seeing you in action, you are extraordinarily capable of fulfilling that leadership role, were you only challenged by it. It takes effort and a certain amount of guts and the will to do it.

Dr. **Brandt**. Yes sir.

Mr. **Scheuer**. Our medical profession is probably equal to any in the world, but it has been said before that like other professions and other peoples, they are sometimes hostile to change, comfortable with the present ways of doing things. They may feel a certain anxiety and sensitivity about having that computer looking over their shoulder. They don't always perceive of the computer as being something that can enhance their professional effectiveness. They look upon it as a sort of watchdog that could embarrass them.

We have heard stories, and testimony that in hospital after hospital, once the effort was made to bring computer systems and assistance and support of physicians into the hospital, however much they may have stonewalled it, and however reluctant they may have been to be dragged into the computer age, once they learned how to dominate and control and manipulate that computer and make it do things for them, they valued it very highly, and do value it highly. But there is a difficult transition period, that information and education period that is necessary.

It seems to me that Government and high officials in HHS could play a great leadership role were they challenged to do so.

Dr. **Brandt**. I agree with you, and we certainly will work with them. My experience has been exactly the same as yours; namely, once you get the machine in there and if the people who design the system have done a good job and it works, that health providers will readily accept it.

The new breed of physicians that is coming out now since the massive increases in enrollment, and the fact that many of those young physicians did their residencies in hospitals that have made use of computers in some aspect of patient care, I think they are much more eager about it.

I had an interesting experience not long ago in Texas. I went down to visit Dr. Mario Ramirez in Rio Grande, Tex., which is in Starr County right on the Rio Grande River. He has a small clinic down there, and he was taking me through it, and we came to a little room back in the back of this clinic—this is a small town—and it was labeled computer room. I went in there and there is where he maintains, certainly basic, not complete medical records, but significant information on a computer that he owns and has set up in his own clinic.

Mr. **Scheuer**. Was he plugged into any tertiary hospital within 100 or 200 miles?

Dr. **Brandt**. No, he was not, but I am sure that as that potential develops, that he will certainly eventually be plugged into such a system. So I think that the profession is ready to accept it, I mean, to accept computers as a adjunct and as an aid to their practice.

Again, I come back to the fact that they have accepted it, and made use of it in those places where it works in a demonstrable, predictable fashion, and that is by and large the handling of physiologic data, which is numerical and can be quantified and can be really dealt with in that fashion.

Mr. **Scheuer**. Well, surely you are not suggesting that the areas where the medical profession has not accepted health information systems and computer applications would mean that they are ipso facto inappropriate for future application?

Dr. **Brandt**. No, no, I am not suggesting that.

Mr. **Scheuer**. You would say at any one point in time, taking a snapshot of today, that the areas in which physicians have accepted the application of computer systems is right and the area where they have not, there is no potential?

Dr. **Brandt**. No sir, not at all. What I am saying is, it will be easier to introduce new working applications in the future than it has been in the past, because they can walk down to their coronary care unit and see that thing working well.

Mr. **Scheuer**. Right. In other words, success feeds successes, as you have proved in a few areas. Once you have proven to physicians that computerized systems can be supportive in one area they are likely to be more receptive in other areas.

What is the present status of the Cooperative Health Statistics System and the Model State Health Statistics Act, which is provided for under the Public Health Service Act?

Dr. **Brandt**. I am going to have to ask for some help with that, Congressman.

Mr. **Scheuer**. If we ask any questions which you prefer to send us a written answer, there is no problem. We can keep the record open.

Dr. **Brandt**. It probably would be better to do that. That will give us a little more of an opportunity to respond.

Mr. **Scheuer**. The National Death Index was recommended by the National Committee for Health and Vital Statistics more than 13 years ago. Why did it take so long, in your opinion—and this predates your service here, Dr. Brandt. Again, I state that no personal criticism is intended at all. Why do you think it took so long to act on that recommendation, and why didn't we make it retroactive, further back than 1979?

Would you like to come up to the table and join us?

Dr. Wunderlich.

Dr. **Wunderlich**. We can give you more details in writing later on, but some of the delay involved negotiations with the State's vital statisticians as vital registration is a responsibility of the States, and it involved a cooperative venture, getting their concurrence and working with them.

Some of the delay was a result of time consuming and complex processing. It is an ongoing activity in the National Center for Health Statistics now and will be operational this year.

Mr. **Scheuer**. Do you feel that it has been useful? Apparently it was created with some travail, and there was considerable resistance and a lot of extended negotiations with the States, and it went over a period of a decade.

Was the game worth the candle, in your opinion?

Dr. **Wunderlich**. We can provide the details, but I think it will be used by States, by the National Institutes of Health for epidemologic research, and from the information I got from the National Center for Health Statistics, we have had already several letters of interest.

[See letter from Dr. Brandt to Walgren/Scheuer.]

Mr. **Scheuer**. That is encouraging. It could be that the State departments of health will come to the feeling someday that there is a resource down there that they can tap into if we were to develop a comprehensive health information service. It would enhance their capability of coping with epidemics and other health problems. They will know the course these problems follow through this computer assisted information source available to them.

Did you detect any such feeling on the part of States after the system was set up and they began using it, did they say hey, this is very useful?

Dr. WUNDERLICH. I wouldn't be able to answer that now.

Mr. SCHEUER. Has the agreement between HCFA and PHS concerning the uniform hospital discharge survey been consumated? Have those issues been resolved?

Mr. CRESSWELL. Bill Cresswell.

The agreement was signed several years ago. I have forgotten the exact year, and we have generally implemented the data set definitions within our program, within the PSRO program and into our billing requirements in medicare generally.

Mr. SCHEUER. Any word on results on usability and whatever enthusiasm there may or may not be out there?

Mr. CRESSWELL. With respect to the medicare program, we run medicare, and our requirements on providers are basically set, and they are specifically for reimbursement purposes. So in terms of the benefitting our providers, generally speaking, no.

I think the benefit might come to researchers as they look at medicare data and medicaid data and private pay data, and put those together for research purposes. Common definitions across all of them will facilitate the kinds of things you are talking about.

Mr. SCHEUER. Let's turn to the National Center for Health Statistics. They presented a plan for collecting and coordinating statistical and epidemological data. Do you know what has been done to implement the recommendations that were included in their report?

Dr. MARGULIES. The report has gone to Congress, but it was an information report with no set timetable to implement recommendations in it.

Dr. BRANDT. The answer is that it has not been implemented yet.

Mr. SCHEUER. And what are the plans for implementing it?

Dr. BRANDT. At the present time we have no plans for implementing it.

Mr. SCHEUER. Do you have any intention to create a plan to implement it?

Dr. BRANDT. We certainly have a plan for me to go back and familiarize myself with it and look at the issue.

Mr. SCHEUER. OK, we will hold the record open.

Dr. WUNDERLICH. A lot of data gaps are mentioned in that report, and as the Department and Public Health Service develop new data systems, those issues that have been identified in that report will be considered as resources are available, but as Dr. Brandt has said, no formal plan has been developed yet.

Mr. SCHEUER. Is there any intention to develop a plan?

Dr. WUNDERLICH. We will be looking at it.

Mr. SCHEUER. Will you let us know?

Dr. BRANDT. Yes.

Mr. SCHEUER. Dr. Brandt, let me address your feeling that the CHIS would be inflexible and rigid. It seems to us that it would be perfectly viable for each hospital or region to have its own information system with its own requirements. There would have to be some consistency on definitions, I suppose, but the data could be recorded on a tape in a standard format and sent to a central data bank, so long as there was an agreement on definitions.

With, I would think fairly minimum planning, any health organization could trap into that central computer bank for any purpose that it wanted.

I don't quite understand why you feel that the computer implies rigidity. It gives an infinity of options and choices.

Dr. **Brandt**. I agree with you. I don't feel that it is in and of itself rigid. I think the tendency of people who design those systems is to make them rigid in the absence of information, that is, in the absence of understanding.

In the first place, it is a great deal cheaper to keep the amount of information at a minimum and to keep the types of processing allowed at a minimum. There will always be a tendency, therefore, to make them more rigid than they ought to be. At least that has been my experience, and in large part, many of those decisions are based upon ways to cut costs. I think you can build in as much flexibility as you can afford, and to the extent that the human brain can visualize what that is.

My principal concern is that as we go about taking the steps that we are talking about to implement this, that we make sure we are not making it rigid.

Mr. **Scheuer**. Correct.

Dr. **Brandt**. That is the destructive side of the issue.

Mr. **Scheuer**. Absolutely.

It seems to me that again your office, or your agency can play a real leadership role in guiding not only the development of a CHIS, but in guiding the uses of it among the various elements of the health and medical community that would be using it, whether it is the pharmaceutical investigators or the hospital administrators, or the county, or the chairman of the county health organization, or the dean of a medical school, showing them the extaordinary variety and diversity of uses and urging them to avoid inflexibility and rigidity.

Dr. **Brandt**. You make me shudder at the thought of the hospital that collects these records, sends them to a central point, and at some point a hospital administrator or anybody else could suddenly decide they could start looking at my medical records. That makes me very, very nervous, Congressman. I don't mind if I have said you can have access to my medical records, but otherwise it certainly makes me nervous to think that is going to happen.

One of the issues involving the kind of situation Congressman Brown brought up earlier about the contaminated water, is in fact trying to walk that thin line between trying to monitor these people over a long period of time, and at the same time not violate their privacy. Since we don't know what we are looking for, we may get into areas we don't need to get into. That is a risk or a danger we have to constantly be aware of.

Mr. **Scheuer**. We can control that privacy, and we can give orders to that computer limiting access to that data. In the Inter-Agency Task Force on the Health Effects of Ionizing Radiation, an entire volume was devoted to personal privacy and the question of researchers' access to the records.

Dr. **Brandt**. I would suggest to you, sir, that the banking industry has not been able to control that completely. It has been possible in a number of instances to get in and get people's financial records out, and not only get them out and make them public as has been done in a number of instances, but to move money around from one to the other. So our ability to do that at this stage is at best limited. I am not arguing that we can't do it down the road, but again, we have to not assume that is a solved problem.

Mr. **Scheuer**. We have a rollcall vote, and we are scheduled to have several after that. Since you are just a couple of blocks away, would it make sense if we suspended this afternoon, and perhaps asked you back after our recess, after Labor Day?

Dr. **Brandt**. That would be fine, sir.

Mr. **Scheuer**. Why don't we do that? We will find an agreeable time and start at 9 o'clock in the morning, so we will know we have an hour at least before the bells start. We have imposed on your patience and your tolerance enormously, and you have shown enormous equanimity and patience. You have answered our questions to the best of your ability the second time. We are grateful to you.

This is an extremely hectic time this last week or 10 days when we are here trying to put together our tax bill for our reconcilation programs, and rather than keep you waiting for several rollcall votes, I think that makes sense, if you are willing to do that. We thank you very much.

Mr. **Brown**. I ask unanimous consent to insert a few closing remarks in the record.

Mr. **Scheuer**. They will be semiclosing. They will be closing for today.

Mr. **Brown**. I will have additional closing remarks at the next session.

[The closing remarks of Mr. Brown follow:]

I would be remiss if I allowed this opportunity to pass without comment. These hearings have, if nothing else, broadened my concept of the potential benefits as well as the problems associated with a concept as far reaching as a Coordinated Health Information System.

Aside from the specific knowledge I have obtained, I have been given a sense of the importance and the need for us to make a start on achieving a mechanism that will improve the flow of health information in the United States. In order to make that beginning, what is needed is a national sense of urgency and importance of the project. We must couple this with a commitment from all quarters.

For proof that these difficult goals are achievable, we have to look no further than the present operation of U.S. business and industry. They have moved quickly and have exploited the vast potential of computers, data banks and information systems, all without any apparent destruction of proprietary and privacy rights. I recognize that we must deal with enormous technical and societal problems, however, the application of high technology in the health care field is long overdue.

I intend to continue to pursue this subject vigorously, and would hope that somehow my own sense of urgency has been transmitted to others.

Thank you, Mr. Chairman.

Mr. **Scheuer**. With repeated thanks for your kindness and tolerance, we will suspend this hearing and invite you back after Labor Day.

[The information follows:]

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August 5, 1981

Edward N. Brandt, Jr., M.D., Ph.D.
Assistant Secretary for Health
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Dr. Brandt:

We would like to thank you for appearing a second time before the Subcommittee on Natural Resources, Agriculture Research, and Environment and the Subcommittee on Science, Research and Technology in our continued joint hearings on a Coordinated Health Information System: Needs, Issues, and Planning.

Your testimony was most informative. Accordingly, we were disappointed when the hearing was adjourned for a roll call vote. As you may recall, it was suggested at that time that you reappear before the joint subcommittees after the August recess. However, we request instead that you reply in writing to a few remaining questions. If you would do so within the next two weeks we can then close the hearing record and expeditiously complete our report on the hearings.

A list of questions is attached. Again, thank you for returning and we look forward to hearing from you.

Sincerely,

Doug Walgren

Doug Walgren,
Chairman,
Subcommittee on Science,
Research, and Technology

James H. Scheuer
Chairman,
Subcommittee on Natural
Resources, Agriculture
Research, and Environment

DW/JHS/ftd

ADDITIONAL QUESTIONS FOR DR. BRANDT

1. During your recent appearance with the Subcommittees you indicated that this was not the time to start planning for a Coordinated Health Information System. Why is this not the right time and what conditions would be required before planning could begin?

2. The National Center for Health Statistics presented a plan for collecting and coordinating statistical and epidemiological data. What has been done to implement the recommendations included in that report?

3. There has been much discussion concerning access to medical records and the problems of privacy and confidentiality. Substantial time and effort have gone into a report by the Interagency Task Force on the Health Effects of Ionizing Radiation. One entire volume of that report was devoted to Personal Provacy and Researchers Access to Records. What progress has been made to implement the recommendations made in this report?

4. How do the present data gathering activities of the federal government collect differential data on the effectiveness of styles of health care delivery such as hospital vs. nursing home care, HMOs, in-patient vs. out-patient surgery?

5. Presently the quality of medical care is monitored using a paper or partially automated patient chart or abstract. If individual medical records were combined, could the resulting data base than be analyzed for regional and national patterns of care?

    a) Would this procedure contribute to containment of health care costs?

    b) With the ability to draw upon individual or aggregated case histories, would medical researchers be better able to study specific medical problems?

    c) Could this process also provide a workable data base for undergraduate and continuing medical education?

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Office of the Assistant Secretary
for Health
Washington DC 20201

The Honorable James Scheuer
Chairman, Subcommittee on Natural Resources,
Agriculture Research and Environment
Suite 2321, Rayburn Building
Washington, D.C. 20515

Dear Mr. Scheuer:

Thank you for your letter of August 5, also signed by Congressman Walgren, about a Coordinated Health Information System. Responses to the questions contained in your letter as well as the information promised during the hearing are enclosed.

I was pleased to participate in your joint hearings on a Coordinated Health Information System (CHIS): Needs, Issues, and Planning. The continuing inquiry made by your subcommittees into this important matter will greatly assist the Public Health Service in determining the most effective Federal role in the development of health information systems. I believe that the hearings have demonstrated the Department's extensive involvement and investment in the CHIS and related concepts.

Again, I appreciate the opportunity to discuss these matters with you.

Sincerely yours,

Edward N. Brandt, Jr.
Edward N. Brandt, Jr., M.D.
Assistant Secretary for Health

Enclosures

QUESTION 1

During your recent appearance with the Subcommittees, you indicated that this was not the time to start planning for a Coordinated Health Information System. Why is this not the right time and what conditions would be required before planning could begin?

ANSWER

I do not believe that the statement above accurately reflects my views as presented during the recent hearings. At that time, I expressed my interest in improving our health data systems so that we could better identify and treat diseases and disability. We should proceed in a deliberate fashion toward the development of computer assisted comprehensive health information systems.

Although we have made tremendous strides in recent years in the communications field, I question the state of our knowledge and, therefore, ability to institute a nationwide, comprehensive computer system at this time. Many issues need to be addressed before we can plan and develop such a computerized system as visualized in the concept paper developed by committee staff for the hearings. For example, the practice of medicine is as much an art as it is a science, and much of medical care cannot be quantified and standardized for appropriate computer input. The implications for individual privacy and confidentiality of information are far reaching and of fundamental concern in a free society. The technical feasibility, the quality and the utility of data contained in such a system, and the costs involved represent some of the uncertainties of such a system that need to be further examined before launching such a venture.

This does not mean that nothing is being done today. Computers are used in many ways as an adjunct to medical care, enhancing the quality of care and life, but not necessarily reducing the cost of care. Many large hospitals already have well-developed computerized record systems. The Department of Defense and the Public Health Service have established systems for their health care beneficiary populations. In addition, the Public Health Service has a number of additional activities underway. The comprehensive system at the National Institutes of Health Clinical Center is another example of an excellent working model for clinical management. These systems are limited to closed populations. However, they allow us to experiment with the various approaches to identify and examine deficiencies and problems encountered in the management of large amounts of data from patients and the implications of such systems for clinical decision-making.

Further, as described in my testimony, through the National Center for Health Services Reseach we are supporting a number of research projects that are already providing us with the kind of information needed before final decisions concerning the design of a comprehensive health information system concept can be made.

I believe, therefore, that at this point in time, in addition to maintaining a visionary outlook, we must be realistic. An incremental approach toward standardization, coordination and integration of our health information systems will serve us both today and in the future.

QUESTION 2

Environmental Health Statistics Plan

What has been done with it?

ANSWER (Also provides response to a question asked at the hearing.)

In response to the requirement of P.L. 95-623, the National Center for Health Statistics prepared and published in 1980 a report, Environmental Health: A Plan for Collecting and Coordinating Statistical and Epidemiological Data which has been provided to the Committee. The Plan has had a relatively wide distribution. The Center continues to receive requests for the report.

QUESTION

Have we implemented the Plan? Is there a plan for implementation?

ANSWER

There has been no formal implementation of the Plan. In fact, the wording of the legislation did not specifically address the issue of implementation. Given the lack of appropriations for implementation and the current uncertainties of future resources for environmental activities, the development of an implementation plan has not been given high priority.

The major thrust of the Plan was to encourage interagency collaboration in environmental health data collection, compilation and analysis. Many of the Plan's recommendations are being implemented in the absence of a formal implementation plan. A number of coordinating committees, such as the Task Force on Environmental Cancer and Heart and Lung Disease and the DHHS Committee to Coordinate Environmental Toxicology and Related Programs, are active in specific environmental areas. The following list describes some of the Center's activities:

National Natality and Fetal Mortality Survey (1980)

> A cooperative followback study involving six agencies, including components of NIH, FDA, HSA and ADAMHA, investigating many factors (including environmental factors, e.g., mother's and father's occupation and radiation and pesticide exposures) not usually included on vital records.

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National Health and Nutrition Examination Survey

EPA, FDA, NIH and DOE items on water quality, carboxyhemoglobin, pesticides and other environmental variables from blood analysis.

Hispanic Health and Nutrition Examination Survey

This planned survey will contain questions on pesticide exposures along with the standard biochemical data.

National Health and Nutrition Examination Followback Survey

This survey is being conducted under a reimbursable agreement with the National Institute on Aging and several other components of NIH and ADAMHA. Persons examined 10 years ago will be re-interviewed to determine risk factors related to current health status.

A Programmatic Interagency Agreement is being developed with the National Institute on Occupational Safety and Health to maximize the sharing of data between the two agencies in epidemiological studies of occupationally-related mortality and morbidity.

The development of an automated surveillance system for the early detection of time trends, geographic trends and the interactions of the two.

An interagency (NCHS, NIH and Bureau of the Census) pilot study of the feasibility of matching 1980 decennial census records with mortality records, through the National Death Index to greatly enhance the vital record information with the census data on social, demographic and occupational factors.

The inclusion in the Council on Environmental Quality's UPGRADE data system of health data from the National Health Interview Survey.

QUESTION 3

There has been much discussion concerning access to medical records and the problems of privacy and confidentiality. Substantial time and effort have gone into a report by the Interagency Task Force on the Health Effects of Ionizing Radiation. One entire volume of that report was devoted to Personal Privacy and Researchers Access to Records. What progress has been made to implement the recommendations made in this report?

ANSWER

Progress has been made in implementing the recommendations in this report.

1. Internal Revenue Code. We are now exploring the possibility of legislation to amend the Internal Revenue Code to permit disclosure of certain limited information from tax files for health research, under carefully controlled conditions to protect privacy.

2. Privacy Act. This Department has published routine uses in many of its Privacy Act system notices to permit disclosure of personally identifiable information for certain research purposes. For example, many of the data systems of the Health Care Financing Administration (HCFA) are now available for research, under controlled conditions, under a system notice published on July 20, 1981 (46 Fed. Reg. 37327-37341).

   Under that routine use, information assembled for Medicare purposes may be disclosed under these conditions:

   (a) It must be for a research, evaluation, or epidemiological project related to the prevention of disease or disability, or the restoration or maintenance of health.

   (b) The disclosure may not violate legal limitations under which the record was provided, collected, or maintained.

   (c) The disclosure must be one that (1) cannot reasonably be accomplished without records in individually identifiable form, (2) is of sufficient importance to warrant the risk to privacy that additional exposure would bring, and (3) has a reasonable probability of accomplishing its objective.

   (d) The information recipient must agree in writing to (1) establish safeguards to prevent unauthorized use of the record, (2) remove or destroy identifiers at the earliest time consistent with the purpose of the project, unless there is a research or health justification for retaining them, and

(3) make no further use of the record except for health or safety emergencies, for further research (with HCFA approval), for audit of the research, or when required by law.

3. SSA disclosure regulations. These regulations have been amended to permit disclosure of certain information (not subject to the disclosure restrictions of the Internal Revenue Code) for research purposes, under conditions similar to those in the routine use of Medicare records described above. (20 CFR 401.325, 45 Fed. Reg. 74916 (Nov. 13, 1980)).

4. Privacy Act — research use of records. The Department has recommended to OMB, in its 1980 Privacy Act Report, that OMB should study the possibility of an amendment to the Privacy Act to permit research disclosures on the same basis as the routine use this Department has promulgated for Medicare records.

5. National Death Index. The Work Group recommended studying the feasibility of making the National Death Index retroactive. We have made informal inquiry of the State agencies as to whether it would be feasible to make the National Death Index (NDI) retroactive. They have told us that it would not be feasible; it would be tremendously expensive, and the State agencies simply do not have the manpower that would be required.

   We estimate that the cost for each year of deaths prior to those of 1979 would be far greater—by perhaps three or four times—than the annual cost of maintaining the system on a current basis. Present annual costs are about $1.2 million. Nearly all States would have to locate their original death records, and then code and key the necessary index and data on computer tape. This would be very expensive, but more importantly, would disrupt the vital statistics programs in many of the States, which are already understaffed and are unable to hire additional staff due to personnel ceilings.

6. NCHS model vital statistics statutes. The model statute for State vital statistics programs has been widely promulgated and has been adopted by every State (although not in the exact form recommended). NCHS works closely with the States by preparing drafts of model statutes, reviewing and commenting on drafts prepared by the State, and/or assisting in justifying the revision to individuals and organizations in the State who will be affected. We also provide assistance to all States in dealing with legislative problems relating to vital and health statistics as they arise during the legislative sessions.

QUESTION 4

How do the present data gathering activities of the Federal Government collect differential data on the effectiveness of styles of health care delivery such as hospital vs. nursing home care, HMO's, in-patient vs. out-patient surgery?

ANSWER

As the Committee is aware, the majority of Federal health statistical activities are undertaken by the Department of Health and Human Services (DHHS), although the Department of Defense, the Veterans Administration, the Environmental Protection Agency, the Consumer Products Safety Commission, the Department of Energy, the Bureau of Labor Statistics and other agencies collect and use health statistics in carrying out their respective missions.[1]

Within the DHHS, the organization of and decision-making structure for health statistical activities, both for general purpose use as well as for program-specific purposes, is further decentralized among the various organizational units of the Department. These include virtually every health program of the Public Health Service, the Health Care Financing Administration, the Office of Human Development Services and other agencies. The National Center for Health Statistics (NCHS), established by statute, is the focal Federal agency for general purpose health statistics.[2]

The Department's Health Statistics Plan for Fiscal Years 1979-1980 presented a framework into which health statistical activities were placed and evaluated.

The following five subject matter categories comprise one rudimentary model or framework into which most of the varied health data projects and systems carried out in the Department can be organized. The preliminary nature and the limitations of the framework are recognized.

---

1. A detailed description of the Federal Statistical System is provided in A Framework for Planning U.S. Federal Statistics for the 1980's, a publication of the Office of Federal Statistical Policy and Standards, Office of Management and Budget.

2. Descriptions of the DHHS current health statistical activities are found in the Health Statistics Plans and Health Statistics Inventory, FY 81. Copies of these documents have been provided to the Committee.

Page 2 - Question 4

1. Health Status - describes measures of the nature and extent of diseases, disability, discomfort, attitudes and knowledge concerning health, and of the perceived need for health care and health services of persons and populations. Based on demographic, socioeconomic and health information, health status measures identify groups in need of, or at risk of needing services. Data for measuring health status are acquired largely from general purpose sample surveys and census sources.

2. Health Care Resources - describes the health care personnel, institutions, agencies, and facilities including their services, equipment, and knowledge and skills. In addition to gross numbers and ratios, data on the relationships between different resources are of great importance. These data are obtained primarily from licensure, certification, and other records and periodic inventories.

3. Use of Health Services - describes the uses and users of preventive and curative health services and health resources and should measure both the volume of use or activity and the persons who use the services. These data are obtained largely from general purpose surveys and from medical and claims records.

4. Financial Aspects of Health - includes measures of costs, prices, charges, and payments that reflect the financing from both private and public sources to create health care resources and pay for their use. The data are obtained from general purpose surveys, from program-specific sources, and from ad hoc flow-of-funds studies.

5. Health Care Outcomes - describe the end results of the health services provided. These are necessary measures to assess the "output" of the health care system and to complete the logical sequence in the conceptual model. The health care outcomes at the end of a particular time period are identical to the health status measures that describe the initial state of affairs for the next sequence of steps in the provision of another round of services; it is an iterative process. Gross measures of health outcomes are derived from program specific sources as well as from general purpose surveys. Because health care outcome measures at the end of a particular period are identical to measures of health status, they are included in the category "Health Status" in subsequent discussion. Thus, health care outcome measures include all of the measures described above as health status measures.

A number of subcategories are possible within each of the broad framework categories. Other classifications are possible, and the development of an appropriate theoretical framework for health data activities is of high priority.

Page 3 - Question 4

Included in the Health Statistics Plan and the Health Statistics Inventory are descriptions of the Department's present health systems and data gathering activities, many of which collect data relevant to the topics raised by question No. 4. The various agencies of the Department, such as Health Care Financing Administration and components of the Public Health Service, maintain or plan data systems which bear on these issues.

For example, NCHS operates a diverse survey and inventory program that encompasses its legislative authorization to collect statistics on: (a) the extent and nature of illness and disability of the population of the United States, including life expectancy, the incidence of various acute and chronic illnesses, and infant and maternal morbidity and mortality; (b) the impact of illness and disability of the population on the economy of the United States and on other aspects of the well-being of its population; (c) environmental, social and other health hazards; (d) determinants of health; (e) health resources, including health professionals by specialty and type of practice, and the supply of services by hospitals, extended care facilities, home health agencies, and other health institutions; (f) utilization of health care, including utilization of ambulatory health services, services of hospitals, extended care facilities, home health agencies and other institutions; (g) health care costs and financing; and (h) family formation, growth, and dissolution.

QUESTION 5

Presently the quality of medical care is monitored using a paper or partially automated patient chart or abstract. If individual medical records were combined, could the resulting data base then be analyzed for regional and national patterns of care?

a) Would this procedure contribute to containment of health care costs?

b) With the ability to draw upon individual or aggregated case histories, would medical researchers be better able to study specific medical problems?

c) Could this process also provide a workable data base for undergraduate and continuing medical education?

ANSWER

The impact on health care costs of such activities is a research issue in which the Department has great interest. As discussed in my testimony, the Department supports much research directed to these concerns. For example, the NCHSR has for over ten years supported research and development directed towards achieving automated medical record systems that could be aggregated, searched, and analyzed. These efforts are typified by the following activities: the definitive evaluation of the El Camino Hospital hospital information system; the development of the Problem Oriented Medical Information System (PROMIS); the development of the Computer Stored Ambulatory Record System (COSTAR); and the establishment of the Rheumatic Disease Databank and the Coronary Artery Disease Databank. These projects are putting into use the tools that will be needed to provide for the aggregation of data and subsequent analysis that your question suggests. Early results indicate that such aggregations of medical data can have the following effects: benefit the patient by improving the quality of care; provide a database and analytic tools for medical research; and provide a dynamic textbook of medicine that will have a significant impact on how medicine is taught and how physicians keep current with the rapidly expanding knowledge base of modern medicine.

QUESTION ASKED AT THE HEARINGS

Status of Model State Law

ANSWER

A number of States have implemented portions of the Model State Law...other States are at various stages of implementation. Utah is the only State so far to have fully implemented it. The National Center for Health Statistics is now making an inventory of the steps undertaken by the States toward the implementation of the Model Law, as well as any problems they have encountered.

The Model State Health Statistics Act is designed to be used by State legislators in developing laws for collecting, sharing, and protecting the confidentiality of health statistics. Such legislators and State health officers are increasingly finding that:

(1) An effective health care system is dependent on the availability of accurate and timely health data.

(2) The confidentiality of data identifying individuals must be assured in order to encourage the voluntary provision of such data.

(3) The sharing of health data by appropriate agencies within and among States and the Federal Government is of mutual advantage and necessary to determine the status of the health care system and evaluate its operation.

The purpose of the Model State Health Statistics Act, therefore, is to encourage States to authorize through legislation an agency in the State to collect and maintain accurate health data, protect health data from unwarranted disclosure, share health data for purposes consistent with those for which they were collected, and coordinate health data activities in the State to eliminate unnecessary duplication of data collection and to maximize the usefulness of data collected.

The Model State Health Statistics Act is the end product of a process which began in 1975. Based on principles formulated by the Cooperative Health Statistics Advisory Committee, a panel of State and Federal experts on statistics, confidentiality, and legislation drafted the Model State Health Statistics Act. The U.S. National Committee on Vital and Health Statistics endorsed the Model Act and urged its promulgation and wide distribution by the Secretary of Health, Education, and Welfare. The Council of State Governments included the Model Act in its publication 1979 Suggested State Legislation. The 1978 Governing Council of the American Public Health Association also recommended its enactment by State governments.

QUESTION ASKED AT THE HEARINGS

Status of the Cooperative Health Statistics System

ANSWER

Current status of the CHSS has been influenced by a comprehensive evaluation of the program carried out by the Office of the Assistant Secretary for Health, by Federal budget policies and by recent legislative action. The recommendations of the panel evaluating the CHSS have led to a redirection away from data collection for national purposes and toward a program for improving health statistics systems by enhancing State capabilities. The panel report placed emphasis on developing the staff capability of the States to better coordinate data collection in the States and to make prompt, effective use of the data.

Recent budget cuts have resulted in the termination of NCHS support for the manpower and facilities components of the Cooperative Health Statistics System. However, the concept of the CHSS translates into significant activity at the State level—38 States have designated State CHSS Agencies and more are expected to do so. Many State Agencies have significantly expanded their functional scope in conformance with the draft NCHS Guidelines for State Statistical Agencies. These guidelines emphasize coordination of statistical activities within States to assure the production of uniform and timely data in an efficient manner, and appropriate access to such data. To enhance the capability of these Agencies, the NCHS funded 12 State Agency Development projects at two levels—planning and coordination for less developed States, and functional performance (data analysis, technical assistance, etc.) projects for more developed States. The results from these demonstration projects indicate continued interest and progress at the State level.

QUESTION ASKED AT THE HEARINGS

Status of National Death Index

Why did it take so long to get it going after Congress appropriated?

ANSWER

The National Death Index (NDI) will become operational in October 1981. This date is within a few months of the recommended schedule developed by the Ad Hoc Working Group to Develop Plans and Procedures for the Possible Implementation of a National Death Index which submitted its recommendations to the Director of the National Center for Health Statistics (NCHS) on August 31, 1978.

Since death registration in the U.S. is a responsibility of the States and because the development of a national death index is a major undertaking, the following complex activities were necessary before the NDI could be made operational:

1. Separate arrangements had to be made with each State vital statistics office for the procurement of death record information required for the NDI, including data from death certificates onto computer tape. Funds for the NDI were awarded in late FY 1979 to 46 of the 54 registration areas to obtain data on 1979 deaths. Contracts were awarded around April 1980 to 51 registration areas (for 1980 deaths), and around April 1981 to 52 registration areas (for 1981 deaths).

2. The processing of each State's data is a complex and time consuming process, involving the monthly receipt of data tapes, the editing of the data, and the conversion of the data to a standard format. The 1979 data conversions for the 46 participating registration areas were completed by March 1981. Authorizations were recently received from the remaining eight registration areas, permitting NCHS to key the necessary data items from these States' microfilm records. This keying activity is scheduled for completion in October 1981.

3. In order to store the NDI data (about 2 million deaths annually) and perform efficient searches of the NDI file, NCHS had to purchase a data base management system and train its employees as to its use.

4. A special program has to be written and tested to perform searches of the NDI file. Minor modifications to this program are now underway and are scheduled for completion in September 1981.

5. An NDI User's Manual and an application form had to be prepared to explain how the NDI operates and NCHS requirements for using the system and to enable investigators to apply for use of the service. This manual and application form are now at the printer, and copies should be available for distribution in October 1981.

QUESTION

Are States recognizing its value and using it?

ANSWER

All States are currently participating in the NDI, and recognize its potential value and eagerly await its implementation. For many States it should reduce the need to conduct large file searches previously requested by numerous investigators. Although the NDI was not designed primarily for use by the States, we expect some State cancer registries and other State statistical agencies will make use of this service.

QUESTION

How much is it used?

ANSWER

NCHS has received numerous letters and phone calls from investigators expressing great interest in the NDI and its specific applicability to their research activities. About 400 individuals and institutions have requested a copy of the User's Manual. However, it is too soon to know the volume of requests which will be received during the next few years.

APPENDIX I

Additional Statements for the Record

Blue Cross
Association
Blue Shield
Association

676 North St. Clair Street
Chicago, Illinois 60611
312/440-6000

June 3, 1981

Honorable Doug Walgren
U.S. House of Representatives
Subcommittee on Science, Research
  and Technology
Washington, D. C. 20515

Dear Mr. Walgren:

The purpose of this letter is to explain the Blue Cross and Blue Shield Associations' perspective on the development of a Coordinated Health Information Systems (CHIS). I am pleased that you requested our input on this issue.

Throughout the health care delivery system there is a continual need for appropriate, accurate and timely information. This need exists for individual practitioners and institutions as well as local, regional, state and national organizations both in the private sector and government. Every sector of the health care delivery system collects and generates great amounts of health care data. Mechanisms are needed to change these data into useful information. A coordinated system for entry, processing and retrieval of information would be an important contribution. Improvements in public policy and decision-making depend upon the availability and accessibility of good data.

Although the need for a unified health information system appears self-evident, there are many questions which must be addressed surrounding implementation of a nationwide network. Issues such as confidentiality, uniformity and reliability and validity of data present serious obstacles to overcome. Because these issues are so important, the development of a health care information megasystem, as proposed by CHIS, which is so far reaching and all encompassing that it anticipates the creation of a new social institution would not be a wise policy to adopt at this time. Some of the specific reasons are:

First, the technology does not exist to create such a system. Scarce resources from the nation's technological manpower pool would be needed as well as an enormous amount of monetary support from the public and private sectors. During a time of austerity in government spending, the appropriateness of allocating funds to such a project is questionable.

Second, the quantity of data to be collected under this proposed national data base would be enormous and the need for it is of major concern. Present information needs should be identified first before attempting to create a system which can satisfy all conceivable information requests. A survey and exploration of the possibilities in coordination of existing information systems should be conducted before imposition of a larger system. CHIS represents a system designed to anticipate future information needs. Much information presently unneeded would be collected. This is a costly and probably unnecessary approach. Much data already exists which are not adequately analyzed or utilized by researchers, institutions and the government.

Third, the reliability and validity of information currently being collected is a major concern. These problems would be exacerbated under the CHIS proposal because of the magnitude of data to be collected. There is presently a large discrepancy between medical records data and discharge abstract data from hospitals as shown in studies by The Institute of Medicine. Such basic problems must be solved before such a data base is relied upon for making the medical treatment decisions proposed by the CHIS. This example is only the tip of the iceberg for reliability and validity of data. The inadequacy of present quality assurance measures for even basic diagnostic coding would seriously jeopardize the usefulness of a nationwide health care information system. Development of appropriate mechanisms to assure reliability and validity for all the sources of data in the system would have to take place. This is a monumental task which in itself would take many years.

Fourth, confidentiality of data is another problem associated with extensive information systems such as CHIS. Control of access to a national health care data base may appear simple and logical on paper, but in reality would be very cumbersome and difficult to administer. Once data exists in a retrievable format, access to the data is merely a matter of having the right code number. If CHIS is to be used for the study of health care technology, drugs and the like, then patient identifiers must be collected. There has been a continuing debate in Congress on how best to protect patients from unwarranted access to and the use of such information by various users.

It is extremely important that the various institutions, organizations and individuals involved in data submission to CHIS understand the need for collection of confidential, financial, medical, personal and other information. The issues of confidentiality and use of data would have to be resolved before any such major project could be successfully undertaken. Congress should address these issues before considering a system such as CHIS.

Fifth, uniformity of data is another area which must be considered. Uniform data sets must be established and uniform coding systems and uniform formats for collection and reporting of data must be designed and implemented before any national data system could be operational. Unless a reasonable level of uniformity is achieved the information retrieved from the system will be of questionable value. The difficulties in bringing about uniformity are evident from examining the development of the uniform hospital billing form. It has taken over ten years to reach agreement on this small part of a health care information system, and even now its adoption by the federal government is not assured.

In summary, although a unified health information system could be very attractive, we question the practicality and the wisdom of attempting to establish such a grandiose nationwide health care information system as CHIS. Reliability and validity of the data, confidentiality and uniformity are only a few of the major concerns which must be addressed. Because of the political and technological problems in these areas alone, we feel that at the present time such a megasystem of health care information is not feasible or appropriate.

Currently many experiments are being conducted which address some of the issues involved in creating health care information data bases on local and statewide levels. For example, HCFA-funded Integrated Data Demonstrations are testing the feasibility of integrating billing and discharge abstract data. Assessments of these experiments should be completed before any nationwide system is tackled. We do not view these demonstrations as fragmented efforts which are detrimental to the establishment of a unified and coordinated CHIS, as suggested in the CHIS proposal. These are instead valuable experiments which examine the problems and benefits of establishing broad health care data bases. It will be difficult to evaluate the information provided by these experiments until they are completed.

One of the lessons of the past decade is that the imposition of a national system may not necessarily be the best approach to take. Further, whatever the theoretical attractiveness of a single solution approach, the practical problems associated with the diversity of our country often make this impossible. Our experience indicates that data is most needed at local and statewide levels where problem resolution can be most effective. The ability to build on local systems should be fully explored. For example, Blue Cross and Blue Shield Plans across the country maintain their own health data bases of claims information. Utilization information is continually being reported to accounts, hospitals and individual practitioners. Superimposing another reporting system on top of current systems merely increases costs without immediate and direct benefit. The private sector and the public sector on local, state and national levels have invested a great deal of time and money in the establishment of information systems. These health care information systems should not be ignored. Coordination and improvement of these local bases should be encouraged. Linking existing systems together is a more profitable and acceptable route to explore than imposing a national directive for a CHIS.

In this letter, we have dealt with some of the broader issues which affect the feasibility of CHIS. To the degrees that more detailed discussion would be helpful, we would be glad to arrange meetings between your staff and our technical staff.

I would like to thank you again for the interest of your committee in the perspectives of the Blue Cross and Blue Shield Associations.

Sincerely,

Larry C. Morris Jr.

Lawrence C. Morris, Jr.
Senior Vice President
Professional and Provider Affairs

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JAMES H. SAMMONS, M.D.
Executive Vice President
(751-6200)

June 4, 1981

SID

The Honorable Douglas Walgren
Chairman
Subcommittee on Science, Research
and Technology
Committee on Science and Technology
U.S. House of Representatives
Washington, D.C. 20515

Re: Coordinated Health Information System

Dear Chairman Walgren:

The American Medical Association takes this opportunity to submit the attached comments on the development of a Coordinated Health Information System (CHIS) for inclusion in the record of hearings held on this subject on June 2-4, 1981.

Sincerely,

James H. Sammons, M.D.

James H. Sammons, M.D.

JHS/dap
Attach.

STATEMENT

of the

AMERICAN MEDICAL ASSOCIATION

to the

Subcommittee on Science, Research and Technology
and the
Subcommittee on National Resources, Agriculture,
Research and Environment
U.S. House of Representatives
Committee on Science and Technology

Re: Coordinated Health Information System (CHIS)

June 4, 1981

The American Medical Association takes this opportunity to comment on the subject of the development of a Coordinated Health Information System (CHIS).

The development and expansion of medical knowledge and information in recent decades has been explosive. It is a fact of life today that no individual can keep track of or follow all of the developments that affect the medical sciences and the practice of medicine. The very fact that all available information and knowledge are not now being totally and efficiently managed has been frustrating to many. With the increasing sophistication of data processing and other computer-based technology, it is now feasible to contemplate development of computerized data bases for the purpose of information dissemination and use.

The development of a full CHIS, as contemplated by the Committee and its staff, would create a national system of health care data collection. Like any new initiative of the scope contemplated within the proposal for CHIS, such a program has a potential to create serious problems in the area of privacy of individuals and the practice of medicine.

A computer-based medical information system, whereby physicians and other health professionals would have access to the latest reported information on medical advances would significantly assist the ability of physicians to treat patients. It is when the proposal leads to large scale data accumulation on the health of individuals that problems arise. These problems center around the area of individual privacy and the risk that such data, once accumulated, will be used improperly to direct medical practice and for purposes unintended by its developers. It is our view that no system yet developed can assure total security (as some of the nation's largest banks have learned), nor can sufficient controls ever be developed that can prevent the improper manipulation or use of data contained in the systems.

Privacy Issues

Medical care is best delivered in an atmosphere of trust and confidence. For optimum medical care a patient must be willing to freely communicate with a physician about sensitive personal matters. It is our view that patients would be less candid with their physicians if they realized that elements of their medical history, diagnosis and treatment, would be placed in a national data system. Out of concern for the privacy of their patients, physicians may choose not to participate in the system or possibly maintain less comprehensive information because of access issues. Our concern extends to billing information as well as medical records. Billing information, because of the data contained therein, can be very revealing as to the patient's condition.

While we understand the potential benefits that can be derived from easily accessible and more complete health care data, we do not believe that these benefits outweigh the inherent risks to individual privacy that the existence of a system such as CHIS would have. Furthermore, health care data necessary for statistical analysis can be acquired through surveys in which patients, physicians and hospitals have the choice of whether or not to participate.

Medical Care

Basic to the American system of medical care is the emphasis on a patient receiving individualized treatment from a physician. This system is based on the fact that people are individuals with different physical and psychological responses to any particular illness and its treatment. Information and data contained in a CHIS, on the other hand, is based on an aggregation of data and information to provide information on large numbers of individuals. Such a system, by its very nature, therefore, is not directed towards individual variation in treatment and response.

We are very concerned that a CHIS could be used to develop national norms and standards of care. Such national norms and standards would not be sensitive to individual needs and circumstances but could become national standards that would discourage variation by physicians because of concern over liability. Such national standards and norms could also have the effect of discouraging the development of new or alternative treatment regimens. Whether a CHIS is intended to develop such standards or not, standards will be an inevitable consequence from the availability of such a data base.

Medical Information Systems

While we have serious concerns over aspects of a CHIS that would contain medical or billing information on individuals, the AMA believes that the development of on-line medical information systems is a definite advancement in medical practice. Unbiased peer-reviewed medical information, as is found in medical texts, reference works, and journals can often provide new insight into a medical problem faced by a physician. The availability of such information from a computer terminal (either in a physician's office or in a hospital) would expand the information available to base a treatment decision on, thereby improving the quality of care available.

The AMA, as one of the largest distributors of medical information in the world, is now looking into the development of such a system to be used as a consulting and educational tool for physicians. While we are pursuing such a system, we realize that there is room for many systems, each providing the quality and type of information and service responsive to those who choose to participate. Such a multiplicity of systems allows for the market to determine the most appropriate form for the system to take and encourages technological innovation in the field. Therefore, we would recommend that the development of computerized medical information systems be left in the private sector instead of a governmentally-based system. It is our belief that through competition, the parameters of medical information systems will develop in the form that is optimum to the system's users, instead of a single governmentally developed system where individual uses would have to be modified to conform with the system's limits.

Conclusion

The American Medical Association advises against the development by the federal government or any private entity of a medical data information system that could compromise the right of individual privacy of any person seeking medical care. We are also concerned that such a system could be used to inappropriately establish national norms and standards of medical practice.

We do support the development of computer-based medical information systems that would exclude any health information that could be identifiable to a patient or provider. We believe that such systems should be developed in the private sector so that system users can have available a number of systems to choose from appropriate to the varied medical needs of patients and to promote innovation of such systems in the future.

APPENDIX II

ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

Invited Paper

Information for Health Care: An Epidemiological Perspective

Kerr L. White

The purpose of information is to improve our understanding of problems and issues, as well as of the relative utility of the choices we face. The power and value of information are governed by the extent to which it is: expressed simply and clearly; delivered at a level of precision commensurate with the importance of the decision on which the information has a bearing; and made available sufficiently in advance of when the decision is to be made, so as to allow its assimilation by people. Usable information generally is regarded as a desirable ingredient in optimal decisionmaking; rarely can it be regarded as the sole ingredient, and hardly ever does it provide a sufficient basis alone for making any decision.

Most personal and political decisions are based on scant amounts of reliable information. Matters of health and health care are no exceptions; the great bulk of individual and collective decisions related to these matters use modest amounts of uncoordinated information of dubious quality. In spite of remarkable progress in the fields of information theory and communications science, the information revolution—in contrast to the data explosion—is in its earliest phase conceptually, technologically, and organizationally.

Information Systems

The purpose of an information system is to improve the acquisition, processing, communication, timeliness, and clarity of valid and reliable observations about a particular topic. The relevant observations come in a variety of forms, are made by many different kinds of observers, and flow through diverse channels. In the absence of systematic organization, few sets of observations are compatible, or even comparable.

Terms and Definitions

Within the lexicon of those who work to improve information and information systems, a plethora of terms and related definitions has arisen. For purposes of the present discussion, the following terms and definitions have been adopted:

Data are established or asserted observations, known entities, so-called facts, measurements, or occasionally a premise or assumption. A datum tends to be unidimensional and by itself usually provides little or nothing by way of insight, understanding, knowledge, or wisdom.

Statistical (numerical) data are "facts" acquired prospectively or retrospectively in a more or less systematic fashion, but not necessarily for an explicit purpose, and not always to influence a previously specified deci-

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Kerr L. White, M.D., is Deputy Director, Division of Health Sciences, Rockefeller Foundation, New York, NY 10036. He is past chairman of the National Committee on Vital and Health Statistics.

The ideas expressed in this paper reflect discussions with many individuals, including the author's fellow members on the National Committee on Vital and Health Statistics and on the Health Program Advisory Committee of the Office of Technology Assessment, U.S. Congress; former colleagues at the Johns Hopkins University; Sir Douglas Black, former Chief Scientist for the Department of Health and Social Security, United Kingdom; and the staff of the Division of Health Statistics, World Health Organization Headquarters, Geneva, in particular Mr. K. Uemura and Dr. Boga Skrinjar, for whom an earlier draft of this paper was prepared. None of them, however, is responsible for the overall contents, observations, emphases, or judgments within this paper.

296 *Inquiry* 17: 296–312 (Winter 1980). Copyright © 1980 by the Blue Cross Association. All rights reserved.

sion. Statistics may be crude or processed and may or may not be accompanied by estimates of the error or bias surrounding their credibility.

The statistical methods employed for acquiring, aggregating, reducing, and processing data, as well as for estimating bias and error, and for other forms of analysis, employ scientific principles and concepts. These are usually quantitative whenever possible, but the use of logic and scientific principles is of much greater importance than is the use of mathematical formulas that manipulate data.

Quantitative (statistical) information may stem from the juxtaposition or transformation of two or more facts or sets of facts (data), so that previously undisclosed or unknown "knowledge" is obtained. The transformation of data into quantitative (statistical) information may be descriptive or analytical and in either case is accompanied customarily by estimates of the credibility of the conclusions, credibility that is based on the use of scientific (statistical) methods.

The estimates of credibility and the principles on which they are based are as critical as the nature of the original observations. For example, a simple but scientifically constructed household survey of, say, attitudes toward family size, using a relatively small probability sample based on aerial photographs of a large geopolitical jurisdiction, may be thoroughly credible and useful for planning health services. By contrast, a much larger body of, say, crudely recorded physiological measures, such as blood pressure, collected by a group of enthusiastic volunteer physicians caring for a haphazardly defined set of patients, may be virtually useless for planning or evaluating health services or practices.

Qualitative information may range from prose pronouncements by authoritarian sources, through subjective assessments of such characteristics as hair color, to codified documents that have varying degrees of popular support or acceptance and differing forms of sanctions for noncompliance or infringement. Such information extends from the putative, through the normative, to the constitutional and legislative. The information may reflect the received wisdom extant at a particular time or place or it may recite lists of legally enforceable practices or punishable offenses. Rarely is any of this type of information derived from applications of the scientific method—but that neither detracts from nor adds to its absolute veracity or practical utility.

The Purpose of Health Information

The purpose of health (or medical) information is: to identify individual and collective health problems; to assess their relative severity and urgency; to estimate their prevalence and social costs; to identify and assess the relative safety, risks and efficacy of various forms of intervention; and to evaluate the relative benefits, costs, and effectiveness of measures advocated for the prevention, control, or amelioration of individual and community health problems. In short, health information, as distinguished from medical information, is concerned with the enhancement of levels of individual and collective health to which present and future populations may aspire.

In many nations, health information is rudimentary at best, particularly when compared to information about topics such as commercial transactions, road building, agricultural crops, tourism, or meteorology. In the best of situations, for example, the recording, classifying, and tabulation of causes of death, when compared to autopsy records or clinical charts, are associated with error rates of 40% to 60% or more. Indeed, there is no evidence that more than 10%–20% of all forms of clinical intervention have any scientific basis for the claims made for their efficacy or safety. To be sure, the quantitative assessment of the impact of health services on the health status of individuals and populations is in the earliest developmental stages. Balance is needed both in selecting the health or medical information to be acquired and in determining the precision of the estimates to be made. Perhaps the relatively low-precision estimating techniques of restaurant proprietors and others should serve as the models, rather than the precise bookkeeping practices of a bank or inventory control system of a diamond mine.

In summary, the codification of what little is known and useful about health and health services at all levels is inevitably a slow process. It is more probable that it will be fostered by clear thinking than by rapid computing or indiscriminant storage of data that can vary widely in accuracy, credibility, timeliness, and utility. Contributions to critical thinking are more likely to prove humane, clinically beneficial, and cost-effective than are investments in unevaluated technology, inappropriate precision, and expensive hardware. When in doubt, it is better to be roughly accurate, timely, and useful than unduly precise, late, and irrelevant.

The Purpose of a Health Information System

The purpose of a health information system is formal organization of the concepts, methods, manpower, equipment, and other resources for acquiring and processing data needed for delineating health problems and hazards, for assessing the relative efficacy, safety, and cost-effectiveness of differing forms of intervention, and for evaluating the impact of services provided on the health status of the populations served. Given the current state of medicine as both science and art, as well as the vagaries of biological processes, personal behavior, and administrative and political processes, available data require highly selective marshalling and processing before they can be transformed into useful information. It is the function of a health information system to guide the processes of identification, labeling (nomenclature), coding, measurement, reduction, analysis, and presentation, so that the resulting estimates are scaled, timed, and presented in relationship to the magnitude and urgency of the decisions to be made. It follows as a general principle that the only data acquired systematically should be those that are known to apply to the process of making important decisions. The importance of a decision is determined by the volume of suffering with which a given problem is associated, the proportion of the population affected, the costs of doing nothing, or the extent of various forms of political pressure.

There is a final purpose to which any collection of data should be dedicated: the production of intelligence, in the original military usage, about health and health affairs. Even the most scientifically garnered data, creatively compressed and imaginatively displayed, are unlikely to influence personal behavior or political decisions unless they are interpreted and presented in the light of the contemporary beliefs, habits, and values. This fundamental truth is as valid on the local level as it is within the World Health Organization.

Characteristics of a Health Information System

With the previously described generic principles and definitions in mind, it is now possible to concentrate more directly on the characteristics of a national, state, or municipal health information system (HIS). In order to serve an entire nation's population, it is usually necessary to recognize and integrate the needs of at least three geopolitical jurisdictions, i.e., those at the periphery, such as villages, precincts, neighborhoods, counties, or communes; those at intermediate levels such as provinces, states, districts, regions, or republics; and those at the central, national, or federal government level. The overall purpose of the HIS is to inform the public, its political representatives, policymakers, administrators, and providers about the nature and extent of the people's health problems, and about the impact of a wide variety of influences and services on those problems.

The underlying concepts should be based on behavioral and learning theory, more recently refined further as *information theory*. The fundamental thrust of an HIS (and its components) should be directed at improving the information and motivation underlying decisions that will enhance health and productivity. The immediate practical concepts and activities should focus on political realities, public education, and useful and usable scientific and technological knowledge. The essential contribution of an HIS is to assist in making the most of resource allocation, both among competing economic and social sectors, and within the health sector—in accordance with agreed-upon priorities—and to educate the public about these matters. The understanding should be clear that it is impossible to indulge simultaneously in profligate expenditures on unevaluated "half-way" technology—directed at some illusory, but ill-defined goal of quality—to achieve equity, if not equality, of access for the entire population while containing health care costs within tolerable bounds. Individual compassion for the individual patient must be tempered by statistical compassion for all the people, if social justice and fiscal prudence are to play any role in the management of health affairs.

Although an HIS may be administered centrally, it is essentially a set of standards and procedures for the *one-time*, practical acquisition of *essential*, *minimum*, *uniform*, and *basic* data sets bearing on health care needs and services. All elements are part of an iterative or cybernetic process in which the benefits associated with the current efforts of the contemporary health care enterprise determine the health status of the population prior to the application of the next set of services. In determining the structure and processes, those responsible for developing an HIS should remember that its only justification is to serve specific needs and purposes in accordance with previously agreed-upon levels of geopolitical aggregation, classification schemes, time periods, and output formats.

Goals and Objectives

Overall Goals

An HIS should strive for simple presentation, including graphic displays of appropriately selected data. The technological capacity to accomplish this is currently available, but that is not the principal problem facing the developers of an HIS. The fundamental task is to create imaginative depictions of critical relationships among the five classes of basic data components in the system: *health status*, *resources*, *use*, *costs* and *outcomes* (or *benefits*). On the one hand it is essential to minimize respondent burden, whether through survey instruments or clinical and administrative records, and on the other, it is essential to communicate relevant and timely intelligence to those who need it. When in doubt, an HIS should be seen as an instrument for guiding future policies and practices rather than as a mechanism for recording historical transactions and unhappy events. In general, it should be the policy of an HIS to prohibit the regular acquisition of any data that are not justified by documentation—based on extensive practical administrative use, or on scientific field trials—so that eventually the data can be expressed in forms that will have a potential, if not early, influence on a substantial decision. It is the objective of "political arithmetic," and specifically of an HIS, to assist in quantifying a population's burden of illness and disability in order to determine certain priorities. Facts should be substituted for subjective opinions and informed intelligence for political pressures.

Specific Objectives

Let us presume, for example, that it is the proclaimed goal of a society or its ministry or secretariat of health to assure equitable access for all to health care services of acceptable quality at an affordable cost. The HIS might need to create measures, develop indicators, and make estimates that reflect changes in more specific and objective areas, such as the following:

1. Geographic, social and financial *equity*, i.e., elimination or reduction of transportation or financial barriers to needed services arising from: unavailability of adequate or appropriate resources; racial, cultural, educational, age, or sex bias; or inability to pay.
2. Assurances that the *quality* and type of care are scientifically and technologically appropriate and acceptable to both the providers and recipients of care.
3. *Efficiency* and *cost-effectiveness* in the provision of health services required for prevention, diagnosis, treatment, and enhancement of health.
4. Payment for or provision of *services for* economically or medically *catastrophic conditions*.
5. *Improvement in health status*, accompanied by elimination of maldistribution of resources and inequitable access.

Impediments to the Achievement of Objectives

Efforts to achieve such goals should be accompanied by public accountability with respect to the progress made. Once again, this requires the conversion of raw data into information, which then is used to develop intelligence about the conduct and soundness of the policies and the achievement of progress toward stated goals and objectives. Examples of the data problems that handicap these functions in actual practice include:

1 Failure to understand the need for adequate and relevant information.
2 Insufficient lead time for planning and development of information systems.
3 Unclear designation of specific authority and responsibility for development and maintenance of those systems.
4 Inadequate collaboration among policymakers, planners, administrators, statisticians, epidemiologists, economists, sociologists, and computer specialists in the design and operation of the systems.
5 Insufficient resource allocation to support the systems.
6 Inadequate internal allocation of resources for analysis and creative presentation of information to the users.
7 Failure to develop constituencies whose active and constructive use of the information justifies the systems and generates a continuing demand for the commitment of adequate resources for their support.

Components and Coordination

Health Information Center

A national, state, or local health information center, with a mandate to establish and monitor standards and procedures for the acquisition of all data and the basic formats of all outputs at the designated level, is a prerequisite for the application of an agreed-upon conceptual framework and attainment of credible performance and cost-effectiveness. Both competent statistical staff and close ties with politicians, policymakers, planners, administrators, and practicing health personnel are essential for success. Although these complex relationships may be more limited at the intermediate and peripheral (e.g., state, county, municipal) levels, they are perhaps of greatest importance because not only are most data found at these levels, but a great many priorities and resource allocations are established at these points. Although there may be a need for fewer staff at each of these levels, they should be trained no less appropriately than those in the more central offices.

The national, state, or local health information center should be headed by a permanent director who is a senior professional official or civil servant. Although reporting directly to the minister or secretary of health for the jurisdiction involved, the director should be sufficiently secure and independent to preserve traditions and practices that make the information generated by this center credible and useful to groups of differing social and/or political persuasions. To deliberately politicize a health information unit is to run the risk of undermining its reputation for objectivity. The unit's long-term capacity to contribute the nonmonetary component of the arithmetical equation used in political decisionmaking processes should be protected carefully. Indeed, the director of a health information center should be regarded as the statistical ombudsman of the people's health and their health services.

In principle, the health information center should comprise three or possibly four *major administrative elements*:

1 A *technological and scientific assessment unit*, which has responsibility for obtaining evidence or conducting studies that bear on the relative efficacy, safety, costs, and benefits of currently used or newly advocated forms of intervention is an increasingly important element, especially at the national or central level. This unit should endeavor to make available to health personnel, politicians, planners, and the public answers to questions such as the following (modified from D. A. K. Black):

☐ What are the aims of the procedure or service in question?
☐ How many people, and of what kinds, are potentially eligible for help from these procedures or services?
☐ What proportion of these people actually get help?
☐ What kinds of people are they?
☐ Who fails to get help?
☐ What determines who gets this help and who does not?
☐ Does this procedure or service do any good or make a discernible difference? If so, how much difference does it make and to whom?

- ☐ What does this procedure or service cost?
- ☐ How do these costs compare with those of potential substitutes?
- ☐ Who pays?
- ☐ What does the public—those served, those eligible but not served, and those ineligible—think about the procedure or service?
- ☐ What impact might the procedure or service make on the demand for or effectiveness of other procedures or services?

Although a computerized information system such as MEDLARS may be suitable for certain applications, the capacity for storing, retrieving, and transmitting all possible information bearing on questions such as those listed above is of trivial importance compared to the task of obtaining credible answers themselves. Where resources are in short supply they should be used for obtaining answers to important questions rather than for processing information of dubious or ephemeral value.

There are other types of information relating to poison control, adverse drug reactions, and management of complex biochemical and physiological derangements that can be stored, updated, retrieved, and transmitted by computers to on-line CRT screens, at considerable cost. However, except where large-scale interactive networks are currently available—and most of these are still in the experimental and developmental phases—it would appear prudent to await the advent of low-cost microprocessors and satellite networks before advocating their adoption, especially in the least affluent jurisdictions. Indeed, since these systems usually serve the needs of those few people with rare or unusual problems, they hardly can justify a high social or resource priority, even in an extremely affluent or profligate community, except for purposes of experimentation and development.

The technological and scientific assessment unit requires the expertise of statisticians, epidemiologists, economists, and computer scientists, and, as such, could be an integral part of the health statistics information unit described in item 3. Its staff also will need to interact closely with clinicians and biomedical and behavioral scientists. In some settings this unit might be separated administratively from the other major health information system elements but, as in the case of a health services research unit, the location of all three under one responsible official has much to commend it, provided that individual is suited to the task by virtue of training, experience, and perspective. In all probability, an epidemiological, as well as a clinical and statistical orientation, would be essential.

Two additional comments are in order. First, a technological and scientific assessment unit is quite different from a health sciences library. The former seeks to identify practical, efficacious solutions to contemporary health problems and clinical measures that are cost-effective and safe. Libraries are repositories for information that may or may not survive the test of time and that may or may not have some ultimate practical or even theoretical value. Second, the sifting of available evidence purporting to document the alleged benefits of various forms of intervention is done best by application of scientific methods, but it is also possible to use modified Delphi or consensus methods, which involve the experience of experts. This method may be employed in the earliest stages of technological and scientific assessment. Indeed, many useless procedures such as cupping, leeching, gastric freezing, portacaval shunts, and certain forms of bed rest have been disposed of, either through the passage of time or by groups of experts meeting in solemn conclave. Although those may be useful expedients, they are poor substitutes for science, and when employed they should be called by their appropriate names.

2 A *health services research unit*, which has responsibility for developing and testing new arrangements for organizing, staffing, managing, financing, and evaluating the provision of health services, is a second important element in a health information center. A close interaction of the staff is needed with those responsible for social and support services, as well as for the personal health services. All of these activities in-

volve the disciplines associated with the technological and scientific assessment unit and the health statistics information unit, with the probable addition of representatives from sociology, psychology, and operations research.

3 A *health statistics information unit* is the central focus of this discussion and the indispensable element in any HIS.

In most settings, on the one hand, it would seem desirable, if not essential, for the health statistics information unit to be designated the lead agency, particularly where major political and administrative emphasis has been placed on the creation of a dynamic health information system for managing, monitoring (surveillance), and evaluating a community's or nation's health care status and its health care enterprise. In such instances, and particularly where an epidemiological, population-based viewpoint prevails, the other two units would fall naturally within this orbit.

On the other hand, where a health statistics information unit has limited its experience to the recording and tabulation of vital events, supplemented by the conduct of the occasional ad hoc survey, and has shown little or no interest in developing statistical information bearing on health problems and health services, the need for a different orientation, and even for new leadership, may necessitate most of the functions subsumed by the three units described here being assigned to some new entity. An exception might be made in the case of responsibility for the registration of vital records. This issue is, for many jurisdictions, a serious consideration. It is less a matter of the importance of this activity than it is a matter of the way in which health information is perceived and used by managers, planners, and politicians.

4 An *archival and legislative unit* could be incorporated with an HIS. This would provide a reference service covering current health legislation, regulations, policies, practices and general problems, the so-called fugitive, or subterranean, literature. Ad hoc studies conducted by the HIS or by research institutes and universities could be referenced or retained here. It is essentially a reference library, serves a bibliographic function, and is not necessarily quantitative.

Principles for Development of an HIS

Here is a summary of selected principles for developing an HIS:

1 Start with a small, appropriately trained staff committed to an agreed-upon conceptual framework and to a set of organizing principles for constructing the HIS.

2 Focus on common health problems that currently affect large numbers of people frequently, cause great suffering, and impair personal and socioeconomic well-being.

3 Express findings in visual (graphic) formats that emphasize timeliness and utility over precision and technical virtuosity.

4 Employ limited sets of basic uniform terms, definitions, classifications, codes, standards, and conventions from the outset, and expand them gradually in a balanced fashion, as needs are demonstrated and resources permit. Do not, for example, emphasize great detail in the coding of deaths from rare diseases at the expense of estimating the number of persons with fever, malnutrition, diarrhea, headache, arthritis, heart failure, or occupational and traffic accidents, which could be treated or prevented expeditiously and inexpensively if resources were used sensibly.

5 Strive to see that all forms of intervention and all personal and environmental services are supported by scientific documentation of their effectiveness and efficiency.

6 Remember that the words "statistics" and "state" have the same origin; the sole value of statistics is to enable the state and its citizens to improve their individual and collective well-being. Health statistics and health information are essential elements of political arithmetic.

Principles for Data Acquisition

The *only* reason that any society creates or permits the existence of a formal, or even informal, health care establishment is to assist its citizens in improving their health and in alleviating their perceived health problems.

From this fundamental premise it is possible to derive eight principles that could guide the creation of a health statistics information system and the data it collects:

1 The data should be *person-specific*. The system must have the capacity to describe health problems, attributes, events, activities, services, and outcomes, for example, in terms of numbers of individuals possessing them. Although it may, in some settings, be desirable and even possible to count all persons in a population, sampling methods are frequently adequate and more accurate for making useful estimates, and they are usually much less expensive.

If the system is not based on person-specific data, different sets of data are subject to the so-called ecological fallacy, which is to say, each data set may relate to a different subset of the population. For example, it is usually more important for a manager to know how many people are severely disabled than it is to know how many disabling diseases, classified by the International Classification of Diseases, exist in the population. Similarly, it may be more important to know how many children are immunized appropriately than it is to know how many immunizations were given by the nurses.

2 The data should be *population-based*. The system must have the capacity to make comparisons within and across geopolitical jurisdictions and over time. This can be accomplished best by the statistical process of standardization, not only for differences in the age and sex structures of populations, but also for such factors as disability, severity, chronicity, urgency, and case mix. For the equitable distribution of resources, on the basis of need, among peripheral and intermediate geopolitical jurisdictions, politicians and planners need such comparisons. They are made best by the calculation of rates in which both numerator and denominator use persons as units; the numerator would be determined using sample surveys of households or clinical records, and the denominator using censuses or population estimates. Nevertheless, the politician is most impressed by, and the manager finds most useful, information expressed as numbers of persons, rather than as rates. The transformation to a population-based number (accompanied by the estimated error) is made readily from a rate.

Comparisons over time within and among geopolitical jurisdictions is needed, in order to determine whether progress is being made toward specified goals and objectives. The frequency with which temporal comparisons are made should be related to the expected rate of change in the phenomenon being observed. For example, acute conditions may change more rapidly than chronic conditions, and treatable or preventable conditions should decrease more rapidly than those for which no treatment is known or available.

Most current statistics bearing on health services tend to be practice-, clinic-, or hospital-based and, in the absence of geocoding (i.e., identifying the person's place of residence), it is impossible to generate population-based statistics. This is a serious deficiency and a major impediment to the use of much health information for setting priorities and allocating resources, especially in peripheral and intermediate jurisdictions.

3 The data should be *problem-oriented*. The system must start with the identification, labeling, classification, and counting of the people's perceived health (or medical) problems. The fundamental task of the health care establishment is to assist in the prevention, resolution, or management of these problems. There is little virtue in making a medical diagnosis, and even less in recording and counting diagnoses, unless the individual patient or the population sooner or later is helped perceptibly.

In most settings throughout the world, approximately 20 common problems account for about one-half of the demand made on health services, and about one-half of these 20 problems are painful. After the list has been extended to the 50 most common problems, the frequency of presentation of a given problem tends to decline rapidly to less than 1% of visits. Thorough appreciation of these relationships is all the more important in light of the renewed emphasis on self-care and primary health care. Personnel and facilities can be sized, deployed, and organized in relationship to the distribution of the problems that beset the living, rather than to the distribution of the diagnostic labels for the diseases that afflicted the dead.

Health problems are perceived initially by individuals, their relatives or friends, and are described in lay terms, not in medical terms, which are code words used by health professionals for their own purposes. In constructing nomenclatures and classification schemes for problems described by lay persons, as well as for problems seen at the level of primary health care, it is important to recognize colloquial terms and to develop dictionaries that incorporate semantic and linguistic equivalents.

4 The data should be *provider-specific*. The system must have the capacity to identify where and by whom a service was provided. The deployment of resources effectively and efficiently implies a requirement that they b[illegible]d to the distribution of the peop[illegible]lems over space and time. To monitor these relationships, as well as the quality, benefits, or outcomes of care, the individual and his problem need to be linked to the provider, and all three to the population served. In addition, it is important for the manager to ascertain that simple, treatable problems are managed at the lowest appropriate levels, at the earliest possible time, and with the least expensive use of resources—and not vice versa, as happens frequently in many affluent jurisdictions.

5 The data should be *procedure-* or *process-specific*. The system must have the capacity to identify the forms of intervention used, in order to enable monitoring of the distribution, quality, and appropriateness of care, and the uses of resources and costs incurred. In general, it is desirable to start with short lists of broad categories of commonly employed procedures, processes, or products, rather than with long classifications of all possible forms of service.

6 The data should be *period-specific*, that is, the system must have the capacity to relate persons and places over periods of time. Again, the precise structure of the recording instruments and methods employed should be related to the decisions to be made and the geopolitical levels involved. For monitoring industrial, agricultural, and traffic accidents requiring emergency service it may be desirable to record time of day, for example, whereas the monitoring of seasonal epidemics may require identification only of the day or week.

7 The data should be *practical*. The system should seek to minimize respondent burden, recording time, and observer variation. Furthermore, the one-time acquisition of data should serve multiple purposes.

8 The data should be *parsimoniously selected*. The system should not countenance the routine (or even ad hoc) acquisition of *any data* for which there is not clearly written documentation that it will be transformed into information that has the high probability, if not the certainty, of influencing a decision of substantial magnitude. A sound rule is: When in doubt leave it out!

These eight primary principles should guide a purposefully constructed HIS. As an aid to their recall they all begin with the letter P.

Operational Considerations

Organizational and Functional Principles

The precise organizational configuration of the HIS will depend upon cultural, economic, organizational, and administrative traditions and functions at each geopolitical level. In general, however, the HIS should be developed from the bottom up, rather than from the top down. Although the leadership, and even the overall design of the system, may originate at the national level, it never should be forgotten that the sole objective of the HIS is to serve the needs of all the people, those who seek services and receive them, as well as those who need but neither seek nor receive appropriate services. At the levels of self-care and primary health care there is rarely, if ever, an inappropriate demand or cry for help. Indeed, even a person who seeks medical care and has no clear physical affliction must have some problem, possibly social or psychological.

It also may be stated, as a general principle, that there should be some statistical staff—even if it is only one person part-time—at each peripheral and intermediate level, as well as at the central or national level. For example, in a population-based, managerially oriented, decentralized health care enterprise, one-half of the staff might work at the peripheral level, and the others might be divided between the intermediate level and the central office. At the central office, there might be at least an epidemiologically oriented statistician, a statistical analyst with training in graphic presentations, and a technician capable of using a large hand calculator or a minicomputer.

As the HIS evolves and its utility is demonstrated, its resources are likely to increase. A fully established HIS for a large, affluent jurisdiction might encompass seven major functions:

1 *Presentation of Information and Analysis.* Although the acquisition of data for an HIS begins with the people and their problems, the output of the system must meet the perceived needs of decisionmakers at all levels, including the politicians, policymakers, administrators, and, of course, the people themselves.

The customary pattern is to spend 10% of the budget and effort on planning data acquisition, 70% on collecting and tabulating it, 15% on analysis, and 5% on presentation. A more realistic approach would allocate 30% to planning the system, 20% to acquisition and tabulation of data, 30% to analysis, and 20% to presentation. If such a scheme were adopted, more than two-thirds of the HIS's resources would be devoted to the planning, analysis, and presentation phases. This involves close liaison with all potential users of the information, especially those responsible for setting priorities and allocating resources and those responsible for managing and evaluating services.

Both present and future needs for information, and the utility of current methods of analyzing and presenting information, should be the subject of frequent frank discussions among all concerned. The unit responsible for these functions should be constantly alert to emerging health problems and issues that are of social, economic, and political concern, as well as to emerging knowledge and technology that could prove efficacious and cost-effective. The design of the system is an iterative process in which the problems to be addressed and the progress to be made are always kept to the forefront.

At least two or three types of publications seem desirable. They should be characterized by brevity, clarity, and graphic presentations wherever possible. Few nonstatistically trained persons can read a table.

At one extreme, a periodic, perhaps annual, report on the state of the nation's health should be issued. It might start by depicting such types of information as the 10 leading health problems—by national, intermediate, and peripheral jurisdictions; the 10 most readily preventable health problems; the ratios of different types of personnel to each other and to different facilities and other resources; the 10 most expensive procedures or treatments; the 10 population groups at greatest risk of succumbing to illness or injury; the 10 hospitals with the highest age, sex, diagnosis, and severity standardized case-fatality rates; or the 10 hospitals, similarly standardized, with the highest bed turnover rates. In addition, each issue might include two or three more detailed chapters examining special problems, such as those of children, the aged, the mentally ill, or those with trachoma, or those sustaining agricultural accidents. These chapters would change from year to year, as public concerns and political or health priorities shifted.

At the other extreme, short, one-page graphic displays with a brief explanatory text should be issued at more frequent intervals, weekly or monthly. Here, the use of suitable health indicators or profiles facilitates the clear and parsimonious display of a considerable amount of raw data. Usually a single topic could be presented, such as level of children's immunizations, progress of an epidemic, or across-area comparisons of rates for procedures of dubious benefit (e.g., tonsillectomies) or of established benefit (e.g., fluoridation of water supplies).

Between these two extremes, and if resources permit, intermediate-sized publications of interest to restricted or specialized audiences could be published. When the data permit, more extensive breakdowns might be provided.

In general, the first two types of publications will tend to suggest what and where the problems are, while the latter type should help to shed light on the causes of the problems, or at least suggest likely hypotheses for further ad hoc studies.

2 *Standards, Conventions, and Procedures for Acquisition and Processing.* Many jurisdictions have little in the way of an HIS, and others have vast arrays of uncoordinated "data systems" with heterogeneous outputs that preclude comparisons over time and place. The latter is a consequence of each "data system" employing different definitions and classification schemes, for example, or using different recall periods or age intervals. It is important, therefore, to have some one person or unit responsible for the promulgation, monitoring, and revision of standards, definitions, and procedures to be used at all levels. At least a core of these standards, definitions, and procedures should be agreed upon by all levels, even if these are expanded in certain jurisdictions or for special purposes. Among the matters to be considered are problems of supervising the overall quality of the HIS, including those of reliability and validity; data acquisition; minimization of reporting burden; confidentiality and privacy; sample design and size; selection of nomenclature; classification and coding schemes; tabulation and analysis formats; and matters relating to the size and utility of each measurement in relation to its associated error, cost, and potential contribution to the problem it addresses. Output conventions relating to such matters as age, sex, socioeconomic level, occupation, education, and geography—as well as the major relationships to be displayed among the five classes of statistical data employed by the HIS—also should be under the purview of this unit.

3 *Terms, Definitions, and Classifications.* Reasonably comparable, if not uniform, health statistics require the use of established terms, classifications, and coding schemes throughout the HIS. Many of these will be international in origin and scope. Although others will be nationally specific, efforts would continue toward the evolution of semantically and linguistically equivalent international practices. Experience has established the value of *uniform minimum basic data sets.* Originally developed for use in the registration of vital events and used on birth and death certificates and related documents, the same principles have been applied in some settings to data sets for ambulatory care, hospital care, long-term care, manpower, and facilities. Similarly, classification and coding schemes could be developed not only for cause of death, but also for lay terms; for terms used in primary health care—including reasons for seeking care; and for hospital care. Also, terms for such attributes as functional capacity or disability, severity, complexity, chronicity and urgency would be useful in a classification system.

4 *Determination and Promulgation of Statistical (Data) Components.* Each of the five fundamental components of an HIS requires at least special attention and, when possible, additional staff to deal with the specific problems of data acquisition and integration within the overall system. Although specific items will vary over time and place, some examples of the classes of data that could be considered are:

Health Status. Symptoms of discomfort, disability, disease, and need for services; clinical health examinations, including psychological, physiological, and biochemical measurements; data on restricted activity, bed disability, coping status, and income loss; data on incidence and prevalence of professionally determined morbidity (diseases, disabilities, accidents, impairments and death).

Health Care Resources. Simple counts of personnel, beds, health centers, hospitals, major equipment, and other tangible elements are the easiest to obtain but perhaps the least useful. Increasing emphasis is being placed on the type and quality of services provided, sometimes including measures of the volume of such services, in order that the competence, effectiveness, and geographic location of the services may be assessed in relationship to measures of health status, particularly of need. Examples might include: rehydration treatments; vasectomies; immunizations; antibiotic injections; tranquilizer prescriptions; brain and body CAT scans; open-heart surgical procedures; inhalation therapies; home care visits; physiotherapy instructions; and therapeutic listening. The health care resource component can be one of the simplest or one of the most complex to measure. The real issue in the management of health resources, however, is not how many doctors, nurses, and auxiliaries there are, or how busy they are, or how many hospitals exist and how high their occupancy rates are, but what services of established efficacy are provided as effectively and efficiently as possible to the people who can benefit most from them. Activity should not be confused with accomplishment.

Use. Estimates both for *persons* using, and for *volumes* of services used, should be developed for primary health care, general hospital care, mental health care, subspecialty care, long-term care, and home care—as well as for use of laboratory, X-ray, and other technologically based services. Volume of services and number of persons cared for must be contrasted, because the object of the exercise is to resolve the individual's health problem as expeditiously and economically as possible, rather than to order tests or make and code diagnoses.

Costs. Capital investments, including initial and replacement costs, and operating costs as well as their associated indirect costs, should be estimated in relationship to both the general populations served and the subsets of those populations who seek or receive services. Where feasible, charges or costs associated with the services should be calculated for the units of service, for the volumes of services and facilities used, and for frequency distributions of services provided per person using them. Again, the emphasis should be on the effective and efficient solution of the patient's problem, not on the activities of the health care enterprise.

Outcomes. Although perhaps the most complex to measure, these are probably the most important. The impact of health care *resources* deployed and of services used at time *A* should have some discernible impact on the *health status* of the population served at time *B*. The information loop is closed with feedback from measures of the *outcome of services* provided. Many of these measures are similar to those used for measuring health status. Other indicators might include: rates for persons with days in pain; consumption of nonprescribed (or prescribed) analgesics, sedatives, or tranquilizers; days homebound; restricted activity days; hospital-bed days; and aberrations in growth, weight, or functional capacity. Much methodological work is needed in this area.

5 *Data Processing.* This is the unit to which many HISs give most attention and on which they spend a major part of their resources. Without diminishing the benefits of the computer or even of electronic data processing, these machines only receive, store, manipulate and retrieve data; they are no substitute for clear and logical thought. They are a means toward an end only. Whether tabulation, storage, and analysis are done centrally or peripherally will depend upon each jurisdiction's size, administrative structure, and resources. Again, it is better to process a little useful information than hundreds of pages of computer printouts that are never used.

6 *Research and Development.* Few jurisdictions will be able to afford the luxury of a staff dedicated to the development of new methods for acquiring and presenting information about health and health services. More narrowly, the work of such a unit might initiate its efforts by creating innovative ways of expressing relationships within and among the five major data components of an HIS. These include multidimensional graphic displays of ratios, rates, proportions for variables of critical interest to managers and politicians. The development of health indicators, indexes, and profiles is still at a rudimentary stage. Methods of standardizing for severity, pain, disability, chronicity, impairment, urgency, complexity, and case mix are all in need of ac-

tive work. Further development is needed for: geocoding; computer mapping; and computer transformations from street addresses, census tracts, blocks, or villages located on a map grid to varying geopolitical configurations. The preparation of do-it-yourself kits for conducting sample household interviews or medical record surveys would be of immense value both for less affluent jurisdictions and for small area studies in densely populated regions. Once solved, the "denominator problem"[1] would enable rates to be calculated for jurisdictions in which a population or panel register, or even a census, does not exist. Similarly, techniques for transforming measures of volume of services into counts and rates for persons served is a worthwhile methodological problem on which little work has been done.

To date, the resources expended on these types of problems have been slight in contrast to those spent on, say, computer simulation or on the modeling of health services systems, particularly when these studies employ data of questionable utility. Conceptual and creative talents in health statistics—in contrast to technical virtuosity—are in extremely short supply. The application of the former talents to fundamental problems, such as those described, is preferable to attempts at solving more esoteric problems. At best, the latter should be left to universities, although their capacities are, of necessity, limited until the appropriate data are available.

Mechanisms

Since statistics, especially health statistics, are the business of the state and hence the people, it is essential to involve persons external to the HIS, or even governments at all levels, in order to develop broad bases of advice and understanding.

Every nation should have an active national health information system committee (NHISC—in the U.S., currently referred to as the National Committee on Vital and Health Statistics), with a rotating membership drawn from users and producers of health information and statistics at all geopolitical levels. Not only health statisticians from operating agencies and universities should be included, but also epidemiologists, demographers, economists, sociologists, administrators, planners, and clinicians (physicians and nurses, especially). The committee should recommend policies and guidelines for overall development of the HIS. In many settings, the committee will be advisory to the minister or secretary of health, and in some settings there will be an analogous internal standing committee to deal with practical problems of implementation. The NHISC should publish a periodic, possibly annual, report commenting on the HIS and proposing changes, additions, and especially deletions of outmoded reports or useless data acquisition requirements.

Analogous committees should be established at state and other intermediate and peripheral levels. Periodically all committees should be brought together for general discussions.

Practical activities of the NHISC and analogous committees can include the use of working parties and technical consultant panels to deal with a wide variety of special problems. Here, membership usually should be extended to include informed lay, or public, representatives. These panels, for example, can determine, and have published, the uniform minimum basic data sets to be used universally for such matters as lay reporting, primary health care, acute hospital care, long-term care, manpower, and facilities. In addition, the panels could develop the following for adoption by legislative bodies at intermediate and peripheral levels: uniform standards for household interviews; epidemiological or examination surveys; uniform standards for protection of the confidentiality of records and individual privacy; and model health information and statistical legislation.

Other panels might deal with the special problems of information needed for the development or improvement of: primary care; the care of mothers, children, or families; or the care of the aged or mentally handicapped. Still others might deal with the need for improved statistics on such matters as environmental hazards, occupational stress, food additives, population dynamics, cigarette smoking, or toxic substance abuse.

In summary, these external groups should not supplant internal bureaucratic arrangements for fostering collaboration and coordination through the mechanisms discussed above, but rather should be used to ensure the widest possible involvement of users, producers, and the public in generating purposeful information that relates to individual and collective health and health services. Again, it cannot be overemphasized that the HIS should be based on learning theory, on information theory, on the notions of feedback and cybernetic loops—not on antiquated conceptions of recordkeeping or data collection. The progenitors of recordkeeping concepts gave birth to the origins of "political arithmetic"; data collection represents the preoccupations of self-perpetuating bureaucracies.

Resources

Personnel. This resource is always in short supply. For example, the number of trained health statisticians (in contrast to biostatisticians, vital registrars, demographers, medical record administrators, epidemiologists, and operations researchers) throughout the world is extremely small. The giants of this field—Petty, Graunt, Farr, Nightingale, Ryle, Pirc, Dunn, Reed, and Sand—have not been replicated. While it is true that they started by counting the dead, their major concern was with improving the lot of the living, and even of the unborn.

Orientation. A large measure of the responsibility for the current state of affairs must be attributed to the separation of "public health" from "private medicine." This division has been institutionalized, on the one hand, in schools of medicine, which have become increasingly preoccupied with molecular events, and, on the other hand, in schools of public health, which have pursued so-called categorical programs for specific diseases, to the exclusion of general services for common problems. Both approaches are removed from the realities of the ways in which individuals perceive and respond to health problems, and from the ways in which health practitioners—traditional and contemporary—try to respond to those problems, especially at the level of primary health care. This issue is central in the design of an HIS. If a health program is conceived of as an aggregation of quasi-independent categorical or specialized activities—some operated in the public sector and others functioning within the private sector with more or less supervision by governments or other publicly accountable bodies—the HIS would try to coordinate the pieces at some central point. This task could be regarded by some as hopeless. If, however, the HIS is seen as the "quantitative (and where necessary, qualitative) ombudsman" of *all* the people, then it is built gradually from the bottom up, using the principles and methods described in this article.

The renaissance of primary health care seems to favor the latter philosophy. If primary health care is to be regarded as the underpinning and infrastructure of the entire health care enterprise, it becomes imperative that at each geopolitical jurisdiction the components of the HIS be restructured from the bottom up. To accomplish this there is a need to reorient the training of health statisticians in universities, to develop intermediate-length (3–6 months) and short-term (2–4 weeks) retraining courses, and to provide manuals (loose-leaf with replaceable modules) and programmed self-instructional texts.

Since the number, type, and level of training and experience of statistical personnel varies widely across jurisdictions, it may be most useful to suggest certain guidelines for establishing priorities for the tasks to be carried out and, by implication, the skills required:

- ☐ It is better to estimate the extent of the most disabling and the most readily treatable problems among the living than to record the causes of death.
- ☐ It is better to focus on the earliest stages of preventable health problems than on the final stages of diseases.
- ☐ It is better to provide a simple chart or graph early than an elaborate table late.
- ☐ It is better to provide what the politician and administrator can understand and use than to provide what fellow health statisticians can admire.
- ☐ Mathematical wizardry and computing virtuosity are not substitutes for clear thinking.

- ☐ Again, it is better to be roughly correct, timely, and relevant than unduly precise, late, and irrelevant.
- ☐ Finally, supply every health care administrator and statistician with a copy of Finagle's "Laws of Information":

> The information you *have* is not the information you *want*!
> The information you *want* is not the information you *need*!
> The information you *need* is not going to be available until the health administrator and statistician start collaborating closely!

Equipment. This resource has been referred to earlier. There is no shortage of computing technology and equipment available, and much more is in sight. Where a three-level system is envisaged and money is no problem, a series of peripheral minicomputers, linked by an interactive network to larger units with more storage at intermediate and central levels, is probably useful. In general, it is best to specify the characteristics of the output desired, the limitations of the input available, then have computer firms design competitive systems and enter competitive bids.

Budget. There is never enough money. If all four administrative elements described earlier (technological and scientific assessment unit, health services research unit, health statistics unit, and archives and legislative unit) are encompassed by the HIS, then a rough rule of thumb would be to spend about 1% of the total annual health expenditures (public or private) on "information." Industries vary widely but, in general, they spend about 1%–5% in this area, including so-called research and development. In any event, whatever funds are available probably are spent better on personnel with analytical capacities than on more electronic gadgetry.

Utilization

The demand for information, whether as formal reports or as special studies, will suggest its utility. The magnitude, frequency, and direction of change in statistical information—including indexes and indicators—should guide the timing of data acquisition and the publication of information. The principle of management by exception is often a useful guide. Analysts responsible for monitoring or surveillance might examine raw and aggregated data for unusual or unanticipated variations and make further inquiries at an individual, institutional, or population level. The review and comments on information at all levels will influence the utility of both the initial input and the final product. The feedback process to lay persons, health care personnel, administrators, planners, and politicians is all part of an iterative sequence that enhances the value of the HIS for the people it serves and who pay for it. Money spent on useless health statistics cannot be spent on useful health care.

Evaluation

Implementation of the principles outlined in the previous sections should provide a substantial amount of continuing evaluation and a number of built-in, self-correcting processes. The several stages of evaluation include: those bearing on the credibility and adequacy of the input; the utility and timeliness of the output; the efficiency and economy of the entire operation, including respondent burden and the time of users to assimilate the information; the impact of the HIS on the overall deployment and management of the jurisdiction's health resources; and, finally, those bearing on the impact of the HIS on the health status of the population.

In spite of continuing efforts at evaluation, most bureaucracies—especially those concerned with what may tend to become routine activities—tend to develop a life and momentum of their own. For that reason, it is probably desirable to have an external commission review the entire HIS periodically, perhaps every five or 10 years. The addition of one or two consultants from outside the jurisdiction may even prove useful in some settings. In the final analysis, however, the most effective evaluation is likely to come from the quantitative demonstration that the HIS has indeed helped to improve the people's health.

Reorientation of Traditional Health Statistical Arrangements

The issue that faces traditional health statisticians in virtually every jurisdiction is: whether to become increasingly, or even solely, preoccupied with the essential tasks of registration of vital events and, especially in the more affluent areas, of assigning identifying numbers to documents; or whether to expand and extend their concepts and methods to develop health information systems directed toward helping the people and their health care enterprise improve the population's health status and well-being. Registration tasks are increasingly simple, technical exercises, akin to the registration of motor vehicles or the issuing of licenses to trade, but they have little to do with health or health care. Even in some developed nations, that almost sacred indicator of medical care, the infant mortality rate, unfortunately is being called into question; there is little doubt of its value in the least developed countries, especially for small-area comparisons. Birth weights and milestones in child development also may be sensitive and useful indicators of both the child's progress and potential, and the adequacy of the available health services.

The difficulties in reorienting traditional health statistical arrangements should not be underestimated. A hardy band of competent authorities will need to set this goal. Articles in professional journals, service on influential committees, discussion with politicians and senior administrators, teaching guides, textbooks, seminars, workshops, and conferences all can play a role.

Where the leaders of traditional health statistics systems seem unwilling or unable to expand and extend their thinking and practices, it may be simplest to reassign them to the registration functions to which their capability is self-limited. The contemporary leader in health statistics inevitably will have to contribute to the dynamic forces and analytic techniques of modern management and government administration, as well as the increasingly practical application of information and organization theories. For example, those responsible for statistics on crops, harvests, the labor force, productivity, foreign trade, currency transactions, economic indicators, and meteorological forecasts have to provide information in timely fashion and clear format for practical use. The same is true of health information: Just as the former activities require a market or social orientation, so the health statistician requires an epidemiological and biological, if not clinical, orientation.

There also is a need to appreciate the limitations of national averages or other aggregated information, and to concentrate on comparisons and differential trends among various standardized rates for the intermediate and small-area peripheral levels.

In summary, survival of traditional health statistics, especially the vital registration component—the vitality of which has been waning steadily in many quarters—may be difficult, if not impossible, unless there are substantial changes introduced, and soon. So urgent are many current health problems that selective analyses of preventable deaths, the results of which could benefit the living, should be encouraged for even such traditional information as causes of death tabulations; this approach has been used effectively for maternal deaths associated with childbirth. It is again a selective and dynamic orientation that is needed, rather than a static one.

Education of Producers and Consumers of Health Information

In the absence of much active leadership from schools of medicine, public health, and hospital administration, the World Health Organization (WHO) has a major opportunity to make a fundamental and enduring contribution to the improvement of HISs. The first director-general of WHO, Dr. Brock Chisholm, introduced a useful and simple health profile 35 years ago. Called the PULHEMS[2] system, it could be adapted readily for use at all levels of health care. It lends itself to quantification and is understood easily by professionals, statisticians, and lay persons. This is just one example; many others of greater or less sophistication could be cited.

It is important to involve the producers of data, that is, the aides, auxiliaries, nurses, physicians, clerks, interviewers, and lower-level managers, in suggesting simple ways of collecting essential data for multiple uses. Whenever feasible, any data bearing on a patient's health or care should be collected on the same document and at the same time the patient is given care, registered, or interviewed. Involvement of the producers of data in the selection of terms and definitions and in the development of nomenclature and classification can be extremely productive. Feedback of selective output of the HIS that has a bearing on the clinician's (or health worker's) practice or on institutional management also can help to improve the quality and timeliness of input.

Consumers of health information should be involved in similar fashion in all phases of the development of the HIS. It may be desirable to start with a so-called Delphi process, which involves asking a number of central, intermediate, and peripheral (including institutional) administrators or managers to list the 10 (or 20) most important decisions they make daily (and/or weekly, monthly, or annually), together with the information they regard as essential or desirable for making these decisions. Such a process could be used to refine priorities, formats, and frequencies of the output to be generated by the HIS, as well as to encourage administrators to use information more purposefully and to support the appropriate expansion or refinement of the HIS and its components.

Most contemporary physicians are not numerate, and few think scientifically. Most statisticians know little about biological and psychological processes and less about the vagaries of clinical practice. The amount of money and the responsibilities for life and limb for which the managers of health care systems or even hospitals are responsible are of the same order of magnitude as those of the managers of airlines or the captains of jumbo jets, yet one hesitates to compare the two groups with respect to their managerial capacities or their insistence on and use of timely, relevant information.

Conclusion

It seems probable that global notions about health, health care, disease, medicine, human welfare, the role of technology, and the fate of the three billion children to be born before the year 2000 are undergoing major paradigmatic shifts. This is not the place to enlarge on these thoughts, but only to emphasize the fact that health information systems have both the responsibility for responding to these shifts and the opportunity to lead them. Finally, it may be worth noting that virtually all of the ideas, concepts and methods discussed in this article have been tried, or are known to be in various stages of development, testing, or application.

References and Notes

1 The denominator problem involves the identification of a statistical method for estimating the population served by a specific physician, clinic, or health center in the absence of any form of registration or assignment by geographical boundaries.

2 PULHEMS is an acronym for: Physique, Upper limbs, Lower limbs, Hearing, Eyesight, Mental capacity, Stability of emotions.